

# **Women's and men's health care utilisation from a cost perspective**

Ingrid Osika Friberg

Department of Public Health and Community Medicine

Institute of Medicine

Sahlgrenska Academy at University of Gothenburg



UNIVERSITY OF GOTHENBURG

Gothenburg 2018

Cover illustration: © 2014, Saskatoon Health Region

Women's and men's health care utilisation from a cost perspective

© Ingrid Osika Friberg 2018

[ingrid.osika@socmed.gu.se](mailto:ingrid.osika@socmed.gu.se)

ISBN 978-91-7833-169-7 (PRINT)

ISBN 978-91-7833-170-3 (PDF)

<http://hdl.handle.net/2077/56911>

Printed in Gothenburg, Sweden 2018

Printed by BrandFactory

*"The world as we have created it is a process  
of our thinking. It cannot be changed  
without changing our thinking."*

Albert Einstein



# **Women's and men's health care utilisation in a cost perspective**

Ingrid Osika Friberg

Department of Public Health and Community Medicine, Institute of Medicine  
Sahlgrenska Academy at University of Gothenburg,  
Gothenburg, Sweden

## **Abstract**

The aim of this thesis was to explore sex differences in health care utilisation and costs (i) in a region in Sweden, (ii) in treatment of dialysis patients across the region, and (iii) in the treatment of specified dermatological diagnoses at an outpatient specialist clinic. Data were retrieved from medical records and health care and pharmaceutical databases, including cost estimates and survey data, and were analysed stratified by sex. The results showed that total per capita cost for health care was 20 per cent higher for women than for men. When total health care consumption was adjusted for reproduction and costs associated with sex-specific morbidity the cost difference declined to 8 per cent. The remaining cost difference could be explained by women's substantially higher costs for mental health problems and diseases of the muscles and joints. Women were more likely to receive less expensive primary care, while men were more likely to receive specialist care. No differences in health-care-related dialysis costs were found between women and men, but the health-care-related costs of patients on in-centre dialysis were more than twice as high as those of patients on home dialysis. Men were more than three times more likely to receive home dialysis if they lived with a spouse compared to if they lived alone – an association that was not found among women. Additionally, patients had a higher likelihood of having home dialysis if they received pre-dialysis information from more sources and if the information was perceived as comprehensive and of high quality. The treatment for eczema and psoriasis demonstrated substantially greater cost for men, whilst women were more inclined to self-care in their home. In conclusion, to ensure the provision of gender equal and equitable health care services, it is important to disaggregate and analyse public health care spending by gender, including the impact of unpaid care work.

**Keywords:** Sex, gender, health care economics and organisations, health care costs, dialysis, eczema, psoriasis, Sweden

ISBN 978-91-7833-169-7 (PRINT); ISBN 978-91-7833-170-3 (PDF)



# Sammanfattning på svenska

Syftet med denna avhandling har varit att undersöka kvinnors och mäns hälso- och sjukvårdsanvändning från ett kostnadsperspektiv på en (i) övergripande regional nivå, (ii) avseende behandling av samtliga dialyspatienter inom en region och (iii) behandlingen av patienter med eksem och psoriasis på en öppen specialistmottagning. Resultaten visar att kvinnor totalt konsumerar 20 procent mer sjukvård jämfört med män. Hälften av dessa merkostnader kan härledas till sjukvårdskostnader i samband med reproduktionen, huvudsakligen förlossningsrelaterat. En ytterligare del förklaras av könsskillnader vid sjukvård i samband med könsspecifika sjukdomar, exempelvis bröst-, livmoderhals- och prostatacancer. Resterande skillnad förklaras av att kvinnor i högre utsträckning än män konsumerar sjukvård vid psykisk ohälsa och vid sjukdom i muskler och leder.

Resultaten visar också att kvinnor i högre utsträckning får vård inom den mindre kostsamma primärvården medan män får mer vård inom specialistvården. Vid dialysbehandling fanns inga skillnader i sjukvårdsrelaterade kostnader utifrån ett könsperspektiv. Däremot var dialys på sjukhus mer än dubbelt så dyr jämfört med hemdialys. Det fanns inga skillnader i den totala hälsorelaterade livskvalitén mellan kvinnor och män, eller mellan patienter med hemdialys och sjukhusdialys.

Resultaten visade en tre gånger högre sannolikhet för hemdialys bland män som bodde tillsammans med en partner jämfört med män som bodde ensamma. Ett sådant samband sågs inte hos kvinnor. Dessutom visade data att patienter som innan dialysstart fått information från fler källor och som uppfattat att informationen var omfattande och av god kvalitet, hade högre sannolikhet att välja hemdialys. Långa avstånd till dialysmottagning betydde också att det var mer troligt att valet föll på hemdialys.

Män med eksem och psoriasis hade tydligt fler behandlingar och högre kostnader jämfört med kvinnor, samtidigt som kvinnor i högre utsträckning hade egenvård, det vill säga behandlade sig själva i hemmet med krämer och mjukgörare.

De samlade resultaten visar att det är viktigt att fortsätta att analysera sjukvårdens behandlingar och behandlingskostnader utifrån ett köns- och genusperspektiv, och att i detta även inkludera den obetalda vårdens fördelning för att säkerställa tillgång till hälso- och sjukvård på ett jämställt och rättvist sätt – och i enlighet med de etiska principerna i svensk sjukvårdslagstiftning.





# List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Osika Friberg, I, Krantz, G, Määttä, S & Järbrink, K. Sex differences in health care consumption in Sweden: A register-based cross-sectional study, *Scandinavian Journal of Public Health*, 2016; 44: 264–273
- II. Osika Friberg, I, Mårtensson, L, Haraldsson, B, Krantz, G, Määttä, S & Järbrink, K. Patients' perceptions and factors affecting dialysis modality decisions, *Peritoneal Dialysis International*, 2018; 38(5), 334–342
- III. Osika Friberg, I, Haraldsson, B, Krantz, G, Määttä, S & Järbrink, K. Health economic comparison between home-based and in-center dialysis, manuscript
- IV. Nyberg, F, Osika, I, Evengård, B. "The Laundry Bag Project" – unequal distribution of dermatological healthcare resources for male and female psoriatic patients in Sweden, *International Journal of Dermatology* 2008, 47, 144–149

# Content

<b>Abbreviations .....</b>	<b>v</b>
<b>Useful definitions.....</b>	<b>vi</b>
<b>Introduction .....</b>	<b>1</b>
<b>Background .....</b>	<b>3</b>
Public spending in the health care sector from a gender perspective .....	3
Health care needs, demand and supply .....	4
<i>Health care utilisation</i> .....	6
Equality, equity and cost-effectiveness – the case of Sweden .....	7
Gender equality and equity in health and health care.....	8
<i>The Swedish context</i> .....	8
Economic theory.....	9
<i>Scarcity, choices and opportunity costs</i> .....	9
<i>Efficiency in health and health care</i> .....	10
<i>Economic evaluation</i> .....	10
Overview of studied disease areas studied in studies II, III and IV .....	11
<b>Aim and research questions.....</b>	<b>13</b>
<b>Thesis overview and methods .....</b>	<b>15</b>
Study design .....	16
Data collection and management .....	16
Data analysis and statistics .....	18
Ethics .....	20
<b>Results .....</b>	<b>21</b>
Study I .....	21
Study II .....	23
Study III .....	25
Study IV .....	27
<b>Discussion .....</b>	<b>29</b>

<i>Defining gender equality and equity in the context of health care .....</i>	<i>29</i>
<i>Cost differences in health care utilisation between women and men .....</i>	<i>30</i>
<i>Informal care .....</i>	<i>31</i>
<i>The health care utilisation approach .....</i>	<i>32</i>
<i>To achieve cost-savings in dialysis treatment.....</i>	<i>34</i>
<b>Conclusion.....</b>	<b>37</b>
<b>Future perspectives .....</b>	<b>39</b>
<b>Acknowledgement .....</b>	<b>41</b>



# Abbreviations

CI	Confidence intervals
DH-Derm	Dermatological outpatient department at Danderyd Hospital
ESRD	End-stage renal disease
HHD	Home haemodialysis
HRQoL	Health-related quality of life
In-centre HD	In-centre haemodialysis
OR	Odds ratio
PD	Peritoneal dialysis
SDG	Sustainable development goal
SPA	Swedish Psoriasis Association centre
UV treatment	Ultra-violet radiation
VGR	Västra Götalandsregionen

# Useful definitions

**How “sex” and  
“gender” are  
used in this  
thesis**

The word “sex” is used in relation to statistics and the biological sex. The word “gender” is used when the social and cultural meanings of “sex” are discussed but also when the significance of sex and gender is mentioned on a more general level.

**Sex and gender**

The concepts of “sex” and “gender” are commonly used to refer respectively to the biological and the sociocultural aspects of being a man or a woman [1]. Chromosomes and external sexual characteristics define the biological sex and assign the legally demarcated binary sex (which constitutes the basis of sex-disaggregated statistics). Gender comprises the construction of “sex” and the relationship between women and men in the social structures of power and hierarchies and is changeable over time and location [2].

**The gender  
system**

Gender and the gender system signify a societal structure that organises human activities and relations based on sex. Although gender studies cover a versatile and growing scope of theory and research, and opinions about gender and the gender system differ, a considerable consensus has been reached in two respects [3]. First, gender implies structures that help to keep apart women’s and men’s work, characteristics and behaviours; that is, a dichotomy [4]. The dichotomy manifests itself in ways such as the division of labour; for example, the fact that workers in the military and building trade are predominantly men and women do most paid and unpaid care for children and elderly [5]. The gender dichotomy also implies that human identity is formed by collective opinions about what is appropriate for women and men, respectively [6] e.g. by gender norms. Second, the relationship between the sexes is unequally divided in a male superiority and a female subordination; that is, asymmetry [4].

**Intersectionality**

Gender and the gender system intersect with other axes of inequality, such as age, socioeconomic position and ethnicity [7, 8]. Intersecting stratification processes can significantly

alter the impact of gender by other dimensions of inequality operating simultaneously in society. The Swedish discrimination legislation include seven discrimination criteria; gender, age, ethnicity, sexual orientation, religion or other beliefs, gender identity or expression and disability.

Gender dysphoria      Gender dysphoria denotes distress caused by a discrepancy between the gender identity and a person's sex assigned at birth. The condition is rare but increasing worldwide. Approximately 0.01 per cent of the total Swedish population had health care contact due to this condition in 2013 [9]. The number of individuals who have changed their legal sex and undergone a sex confirmatory medical treatment between 1960 and 2011 was approximately 0.009 per cent of the total Swedish population [10]. Despite the low prevalence of the condition, implications for optimal medical treatment should be considered.





# Introduction

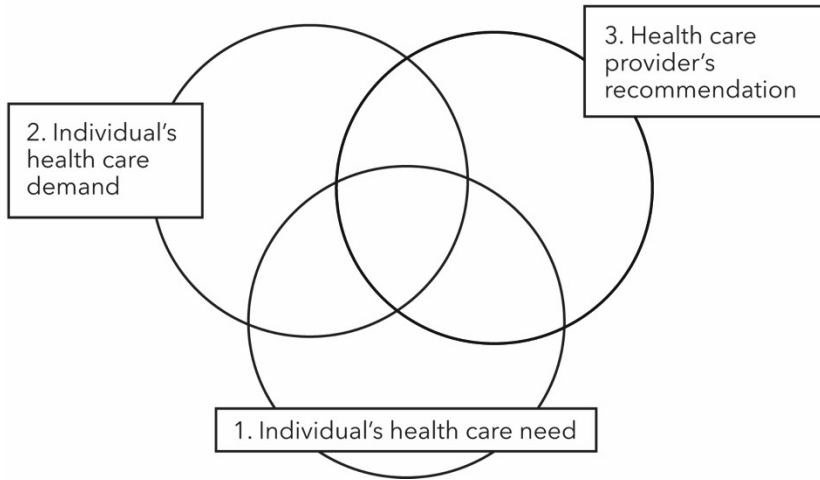
A fundamental objective for governments in many countries is to reduce inequality in the population, mainly through reallocation of resources through taxation, public spending and regulations [11].

Recent decades have seen a rising interest and demand for investigations and analyses of how public resources are distributed between women and men and how they support and interact with the needs, conditions and preferences of women and men [12]. In Sweden, where a tax-funded health care system covers the entire population, health care constitutes a large and important part of public spending, corresponding to 14 per cent of total public expenses [13]. The annual cost of the Swedish health care sector amounted to 500 billion SEK ( $\approx$ 50 billion Euros) in 2016.

Differences between women's and men's health care utilisation have become increasingly evident [14] but remain a rather complex issue. First, a question that is largely still unresolved is how these differences manifest themselves, for example, in and between different treatments, diagnostic areas and health care sectors [15]. Second, what are the underlying causes behind the existing differences, and are they medically motivated? A third question relates to what the differences really imply regarding, for example, outcomes and resource allocation.

There are many potential explanations for why health care utilisation differs between women and men. To put the studies in this thesis in a wider context, the health care service utilisation approach presented by Liss (1990) [16] (see Fig. 1.) can be employed as a conceptual basis of explanation. This approach can help clarify the theoretical distinction between women and men's health care needs and demands, as well as the role of the health care provider's recommendations; that is, the supply side.

Another important issue is what distribution and outcome can be considered just and fair; that is, what do gender equality and equity really mean in the context of a publicly funded health care system? Additionally, because the health care system operates within the boundaries of limited resources, it is important to use the available health care resources in a way that balances efficiency against other priorities.



**Figure 1.** The health care service utilisation approach (Liss, 1990) [16]

Despite the fact that the health care sector consumes a large amount of public resources and the large extent of health care service research, differences between women's and men's health care utilisation from a cost perspective remains largely unexplored, both at an aggregated level and within specific medical specialties.

This thesis explores sex differences in total health care utilisation and costs in a region in Sweden, the treatment of a specific condition across the region and the treatment of specified diagnoses at an outpatient specialist clinic.

# Background

## Public spending in the health care sector from a gender perspective

The approach to disaggregating and analysing public spending by gender was advocated by the United Nations (UN) Fourth World Conference on Women held in Beijing in 1995, and emphasised in several paragraphs in the resulting document *Platform for Action* [17]. This approach has gained considerable attention among international organisations and governments, as well as within research [12, 18-26], and is often referred to as “gender budgeting” or “gender-responsive budgeting”. The overall intention is to “follow the money” and to see how governments raise and spend money – who pays and who benefits, and whether it is equitable. Apart from promoting a more equitable resource allocation, gender-responsive budgeting analyses are considered to lead to efficiency gains in policy making and public spending and to enable accountability and transparency of the public economy [27].

An early advocate of gender budgeting was Diane Elson (1992, 1995) [28, 29], who was involved in the development of the gender budgeting approach. She highlighted the relationship between public expenditures, e.g. public services, and unpaid care work i.e. informal care. Elson showed that when public services were cut back, females had to bear the bulk of the burden because of an increase in the unpaid care work in the home, replacing the reduced public services. Likewise, the time that women had available for market work was reduced, resulting in a private income loss and a loss in productivity in the society as a whole. Therefore, the gender budgeting approach suggests that value should be attached to time spent in the informal care economy and that this information should be used in assessing the benefits and costs of governments and other public programmes and spending [27]. This approach is also clearly traceable to the UN’s agenda for women’s empowerment, *Platform for Action*, mentioned above.

Around 80 countries have started to analyse public income and expenditures from a gender perspective [25]. Analyses have been made with different approaches and in different areas, such as within the educational sector and in relation to the labour market.

However, few studies have disaggregated and analysed public health care spending by gender. The demand for such analyses was pointed out back in

2002, when the National Board of Health and Welfare in Sweden reviewed and analysed gender equity trends in health care [14]. Their findings resulted in a strategy to make health care services more gender-sensitive, including a call to distinguish statistics and data – on activities, treatment outcomes and resource allocation – between females and males. World Health Organization (WHO) Europe recently advocated gender budgeting in the health care sector in order to strengthen women's and men's health, presented in the context of achieving the UNs sustainable development goals (SDGs) [30, 31]. The focus of this strategy is mainly on SDG3; good health and well-being, SDG5; gender equality and SDG10; reduced inequalities. Gender budgeting is advocated as a priority action to strengthen governance for women's and men's health (with reference to SDG16: peace, justice and strong institutions):

*“Integrating gender budgeting across health policies and programmes for more efficient financing of the health priorities for both men and women and for promoting gender equality.” [31]*

## **Health care needs, demand and supply**

Health care demand in a publicly funded health service organisation is mainly a consequence of patients' health care needs, how these needs are perceived and barriers to seeking health care [32, 33]. The degree to which demand leads to health care utilisation also depends on priorities set by the health care provider; that is, which health care services are provided, prevailing evidence-based clinical guidelines, and the extent to which health care professionals identify needs and treatments accordingly. Political priorities and systemic and structural factors, etc. in the health care sector and in society at large are also influencing health care utilisation [32, 33]. In all these overlapping fields, sex and gender are assumed to play an important role. Figure 1 illustrates *the health care service utilisation* approach, and the three basic concepts of need, demand and the health care provider's recommendation; that is, the supply side.

Starting with the need dimension, it is well documented that there are a variety of “social determinants of health”, which refer to the general conditions in which people live and work, which influences their ability to live healthy lives. The social determinants of health are often described by a model [34-36] in which different layers of influence act together to generate the health of people and populations. *Individual factors*, which are at the centre of the model, include age, sex and congenital conditions. The next level corresponds to *individual behaviour and lifestyle* and includes eating, drinking and physical

exercise habits. The third level includes *social and community influences* such as friends' and relatives' provision (or non-provision) of support. An additional level includes individuals' living and working conditions and access to essential goods and services such as education and health care services. Lastly, there is an over-arching structural level that includes the political, economic, cultural and environmental conditions prevalent in society as a whole.

Gender and sex have been identified as major determinants of health, and hence, health care needs [37, 38]. Biological sex is at the core of the model. The gender system, however, is localised in the cultural sphere in the outermost layer where it overrides and influence all the other layers.

Differences in women and men's biological conditions result in different health care needs. Salient examples are needs connected to the asymmetric biological burden of reproduction, but also other clear sex-specific conditions. Other conditions are less well understood and are to some degree linked to biological differences and morbidity risks, such as differences in life expectancy, cardiovascular disease and osteoporosis [3, 39-41].

In addition, gender norms, socialisation patterns and structures in the family, in the labour market and in the public domain lead to differences in the disease spectrum [15, 42, 43]. Compared to men, women generally have lower status, less influence [44], lower salaries and greater stress levels in the workplace [45-48] and perform most of the unpaid work in the home [42, 49-52]. Women are also overrepresented in occupations in the health sector and social care that tear on muscles and joints [53, 54], and have greater exposure to intimate partner violence [55, 56]. Men are exposed to more accidents, including fatal accidents in the work place, exhibit greater risk behaviours (in relation to alcohol and violence, for example) and commit suicide more often [31]. Moreover, studies show that cultural gender norms form barriers preventing men from seeking health care to the same extent as women since they imply that weakness and need for help are not masculine traits [57-60]. In addition, Swedish data show that men consume more avoidable hospitalisations compared to women, i.e. avoidable if they had received adequate outpatient care [61]. Obviously, the gendered patterns affecting women's and men's health may vary in relation to other axes of inequality, such as age and socioeconomic position [62].

Nevertheless, the biological and social conditions that affect female and male health are not entirely separate variables; rather, they interact in the formation of health and illness in women and men [63, 64].

Hence, the sex and gender aspects of the social determinants of health are supposed to have a profound impact on women's and men's needs and subsequent demands for health care [37, 38], referring to areas 1 and 2 in Figure 1. The health care sector, also included in the social determinants of health, is discussed separately (*vide infra*).

Another reason for sex differences in health care utilisation, being more at the supply side, is insufficient awareness of gender norms among health care personnel. Evidence suggests that women and men sometimes receive medically unmotivated treatment differences [2, 14, 65-70] and that men occasionally receive more resource-demanding treatment than women, even when the illness is the same [71, 72]. Research shows that gender plays an important but not necessarily appropriate role in medical decision making [65]. However, insufficient awareness regarding conditions requiring sex-specific differences in treatment to reach optimal outcome has also been noted [43, 73-75].

### *Health care utilisation*

On the aggregated level, there is ample evidence indicating that several patient characteristics influence health care utilisation, the most important being patient age [76, 77]. However, factors such as sex, socioeconomic status, ethnicity and immigration status also influence individual health care consumption [76-80]. Several studies from high- and middle-income countries have demonstrated the effects of sex on health care consumption [76-83]. The results suggest that women generally consume more health care resources, especially primary care, than men. One reason for this difference is the prevalence of conditions related to reproduction; such conditions are predominant among women undergoing pregnancy and childbirth.

One tool that can be used to better understand the demand for health care is the Grossman model [84]. In this model, health is viewed as a capital good that is depreciated over time. Individuals demand health (not health care), since they want to feel good and because it increases their number of healthy days available for work and leisure time. However, to make investments in health, individuals have to spend time and money on health-improving efforts, including health care visits. The model therefore predicts that individuals' investments in health during an earlier life-cycle stage lowers or postpones subsequent morbidity. This should be reflected in less time per year in hospital for groups that received more (preventive) health care services in previous years, everything else equal.

## Equality, equity and cost-effectiveness – the case of Sweden

Governments and international organisations such as the World Health Organisation often propose the objective of reducing inequalities. In Sweden, the opening paragraph in the Swedish health and Medical Services Act (Law 1997:142) is based on an equality and equity foundation (see below). The ethical platform for health care priority-setting [85, 86], which describes the intention of the law in more detail, has become a central guiding principle for the Swedish health care sector. The ethical platform comprises three principles that are explicitly ranked, with the first taking precedence over the second, and

*2 § The goal of the health care system is good health and care on equal terms for the entire population. The care should be provided with respect for the equal worth of all people and the dignity of the individual person. Those who have the greatest need for health care should be given priority. (Law 1997:142)*

the second taking precedence over the third. The first is the human value principle, which states that all human beings are of equal value and have the same rights regardless of their personal characteristics or function in society (refers to non-discrimination in the health care sector). The second is the need and solidarity principle, which states that resources should be distributed according to need. If prioritisation is necessary, resources should be given to those people in greater need (that is, those with the most severe condition and those with the lowest quality of life). Third is the cost-effectiveness principle; that is, if a choice is to be made between different interventions, a reasonable relationship between costs and effects (measured in terms of improved health and quality of life) is to be achieved.

The relationship between the need and solidarity principle and the cost-effectiveness principle is such that patients with severe diseases and substantially impaired quality of life should take precedence over those with milder cases, even if this health care involves “substantially” greater costs for a given health benefit.

The first principle in the ethical platform refers to non-discrimination (an equality concept), while the second refers to need and solidarity (an equity concept). Hence, it is important to investigate what these concepts mean in terms of sex and gender in the health care context.

## Gender equality and equity in health and health care

Debates about gender justice are common in public policy in general and in the health care sector in particular and the terms *gender equality* and *gender equity* are used frequently [37]. However, what are the differences between these concepts?

“*Gender equality* means the absence of discrimination on the basis of a person's sex, in opportunities, allocation of resources or benefits, and access to services. [...] *Gender Equity* means fairness and justice in the distribution of benefits, power, resources and responsibilities between women and men. The concept recognises that women and men have different needs, power and access to resources, and that these differences should be identified and addressed in a manner that rectifies the imbalance between the sexes.” WHO 2002: 3 [87]

The United Nations adopted *gender equality* as its preferred term since the fourth world conference on women in Beijing (1995) [37, 88] and the notion has since been adopted by the majority of organisations and institutions charged with reducing inequalities between women and men. The concept of *gender equity* was considered to potentially allow social and cultural differences between women and men to persist, and was therefore frequently rejected.

The World Health Organisation and other international organisations that manage health issues continued to use both terms – *gender equality* and *gender equity* – since they considered the notion *gender equality* to be too narrow and not to consider differences concerning health conditions and health care needs, such as those originating from biological sex differences [37].

When it comes to education and employment, Payne and Doyal (2012) emphasised, it is social obstacles alone that prevent *gender equality* in terms of outcomes. However, in the context of health and health care, they claim, *equity* should be a crucial concept alongside *equality* since the biological sex differences between women and men prevail and are major determinants of health and health care needs. Failure to recognise this can create further inequalities between women and men [37].

### *The Swedish context*

The *gender equality* policy in Sweden states that women and men are to have the same power to shape society and their own lives. From this key objective, the Government is working towards six sub-targets: power and influence, economic independence, unpaid housework and care, and men's violence



against women [89]. Since 2016, two additional sub-targets have been added to the previous four; gender equality in health and care and gender equality in education. The former is defined as:

“Women and men, girls and boys must have the same conditions for a good health and be offered care on equal terms.” [89]

In a recent Swedish thesis, Smirthwaite [67] stressed that there are many similarities between women and men, but also differences, which the health care providers must consider in the provision of health care. If women are treated on the basis of knowledge and practices based on men (on a male norm), it may lead to inequalities, even if the treatment is the same. The same occurs if men are treated on the basis of knowledge that was mainly based on research on women. To achieve *gender equality/equity* in the health care sector (Swedish; *jämställd vård*), Smirthwaite stated, a prerequisite is that both health care services and medical research acknowledge that women and men are partly different and partly similar [67]. Smirthwaite states that Sweden has no established definition of *gender equality/equity in health care* (Swedish; *jämställd vård*) that all stakeholders accountable for health and health care services have agreed upon [67].

## Economic theory

### *Scarcity, choices and opportunity costs*

Economics is the science of how choices are made in the context of scarcity. Because resources are essentially limited, choices have to be made. When a choice is made, resources are forgone and cannot be used for something else. Choosing to spend resources in one way implies an opportunity cost; that is, the value of the best alternative to what was chosen [90].

Opportunity costs may involve resources measured in monetary terms (such as prices for goods and services) or/and as time spent, such as a forgone day of work or leisure time [32].

Time spent on informal care can be valued as a production shortfall; that is, as a wage cost. An alternative valuation method is the replacement approach, valuing informal care in terms of what it would cost to have a professional health care personnel providing the care [90].

Since it is not possible to meet all needs, demands and wishes with the resources available, choices have to be made about how to use them in the “best” way. “Best” refers to a choice that will give individuals the most satisfaction or utility or maximise population welfare; that is, the aggregate utility of a population.

### *Efficiency in health and health care*

In a health care context, the objective is to pursue both efficiency and equity. Efficiency refers to maximising benefits – that is, utility in terms of health gains – with the resources available (or minimising costs for a given level of benefit). A commonly used efficiency definition is Pareto efficiency [90], a state where the resource allocation corresponds to a maximisation of benefits and where no one can gain without someone else being made worse off. A more versatile definition is the *potential* Pareto efficiency (or the Kaldor-Hicks criterion) [91, 92], which states that welfare improvements can be made as far as those that are made better off can “hypothetically” compensate those who are made worse off.

### *Economic evaluation*

Economic evaluation is an approach that can assist when judgments have to be made that concern efficiency in resource allocation. According to Drummond et al. (2005) [90], two features characterise economic evaluation: it is a comparative analysis (that is, it compares two or more different options) and it compares these options in terms of their costs and consequences.

There are several different categories of health economic evaluations available, where the main distinction refers to the consequences being measured, usually implying some kind of health unit or health benefit. Furthermore, a health economic evaluation requires a cost analysis in which costs for two or more different treatment alternatives are identified, quantified and valued in monetary terms. The costs to be considered depend upon the perspective. A societal perspective includes all costs within the society as a whole, such as consumption of health care resources, out-of-pocket expenditure for the patient and their family, productivity losses and costs of informal care. Another, more limited perspective is that of the health care system, which only includes costs borne by the health care sector.

## Overview of studied disease areas studied in studies II, III and IV

Chronic kidney disease	<p>In patients with chronic kidney disease, the functioning of the kidneys gradually decreases over a period of time (a decreasing glomerular filtration rate) [93, 94]. Initial treatments are pharmaceuticals, remaining active, and dietary changes [95]. When renal function has deteriorated to 10 per cent of the kidneys' normal ability, an end-stage renal disease (ESRD) is at hand. The number of patients with chronic kidney disease including ESRD is growing worldwide [96]. The increase of ESRD is mainly driven by population ageing, increased prevalence of type 2 diabetes mellitus and hypertension [96, 97].</p> <p>End-stage renal disease ultimately leads to the need for renal replacement therapy, including kidney transplantation and dialysis. Most patients on dialysis use in-centre haemodialysis. Other available options include the home-based alternatives of peritoneal dialysis and home haemodialysis.</p>
The choice of dialysis treatment	<p>In several countries, including Sweden, patients with threatening ESRD are informed about different dialysis treatment methods, unless transplant is an available opportunity. In consultation with their physician and dialysis specialist nurse, patients should then be given the opportunity to choose the dialysis method that is most suitable for the individual patient. Consideration can, for instance, be that elderly and severely ill patients may have difficulties in managing home-based dialysis, which would require home health care services.</p>
In-centre haemodialysis (In-centre HD)	<p>In-centre HD is carried out in a hospital or dialysis centre and implies regular visits, usually three times a week for approximately four hours' treatment each time. The patient is then connected to a dialysis machine through tubing, attached to a fistula or a graft inserted in the patient's arm, for example. The blood is then filtered through the machine and waste products and fluids are removed from the blood. In some clinics, patients can be trained to manage some or all of the dialysis procedure by themselves.</p>
Home HD (HHD)	<p>Home HD means that the patient is managing the haemodialysis by him/herself at home. This requires training as well as some reconstruction in the home and space for a dialysis machine and storage of dialysis-related consumables and materials.</p>

Peritoneal dialysis (PD)	PD is also managed in the home by the patient, after a period of training. This method requires a catheter implant in the patient's abdominal cavity. Dialysis fluid is then transferred into the abdomen through the catheter and remains there for several hours while waste products are removed. The dialysis fluid is subsequently tapped out and new fluid is filed in. This method also requires space in the home for storing of fluids and materials. There are three different versions of PD: (i) continuous ambulatory peritoneal dialysis (CAPD), meaning manual fluid changes are done approximately four times a day; (ii) automated PD (APD), which is a machine operating the exchange of fluids during the night; and (iii) assisted CAPD or APD, meaning the patient receives assistance from a home health care service in managing the dialysis process.
Psoriasis	Psoriasis is a common chronic skin disease affecting between 2–3 per cent of the world's population, including approximately 250,000 to 300,000 people in Sweden [98]. Psoriasis often flares up periodically and, in its most common form, is characterised by well-defined red plaques on the skin. The plaques are building up a severe amount of new skin cells. Skin symptoms include pain, itching and cracking.
Eczema	Atopic eczema is a chronic inflammatory itching skin disease. The disease is increasing in countries with good hygiene and good living standards, such as in Sweden. About 20 per cent of preschool children suffer from atopic eczema, as well as 8 per cent of other children and 8–10 per cent of the adult population [99].
Treatment for psoriasis and eczema	Most patients with moderate-to-severe psoriasis and eczema will be referred to a specialist in dermatology in an urban area. The alternative treatments offered in 2003 for these conditions were: bathing and ultra-violet radiation (UV treatment) at a hospital or self-treatment at home. Patients are always prescribed topical treatment and emollients, either to supplement hospital treatment or as a stand-alone treatment.

# Aim and research questions

The overall aim of this thesis is to explore, from a cost perspective, patterns in women's and men's healthcare utilisation. The specific questions are:

- What are the differences between women's and men's total number of contacts and health care costs in different age groups and levels of care? Which differences can be explained by reproductive and sex-specific health care? What are the differences between women's and men's health care costs within the four most expensive disease areas – cancer, cardiovascular disease, diseases of the muscles and joints and mental health problems?
- Are medical factors, patient characteristics, scope and quality of received dialysis information, attitudes and perceptions towards home-based and in-centre dialysis associated with gender and current dialysis methods?
- What are the differences in public health-care-related expenses and health-related quality of life between women and men using different dialysis treatments and between patients with home-based and in-centre dialysis?
- Are there differences between women and men diagnosed with eczema and psoriasis, in terms of subsequent treatment and treatment costs?



# Thesis overview and methods

This thesis comprises the examination of sex differences in health care utilisation and related costs as presented in Table 1.

**Table 1.** Overview of the four studies in the thesis

Study	Aim	Participants	Data analysis/statistics
		Data collection	Gender/sex
<b>Study I:</b> Sex differences in health care consumption in Sweden: A register-based cross-sectional study	To examine (1) total number of care contacts and costs for women and men and (2) to determine the impact of care due to reproduction and sex-specific morbidity. (3) To examine sex differences by age group and level of care. (4) To analyse sex differences in the distribution of costs in the four most expensive disease areas.	Approximately 1.2 million consumers of publicly financed health care services during a year in VGR	Quantitative: Comparisons of costs and contacts
		Register data and health care costs	Impact of sex on health care consumption
<b>Study II:</b> Patients' perceptions and factors affecting dialysis modality decisions	To examine factors affecting women's and men's choice of dialysis method; medical factors, socio-demographics, distance to dialysis centre, scope and quality of dialysis information, perceptions towards different dialysis methods.	N=434	Quantitative: Logistic regression
		Questionnaire comprising a health literacy approach	Impact of gender on modality distribution
<b>Study III:</b> Health economic comparison between home-based and in-centre dialysis	To examine differences in public health care-related expenses and health-related quality of life (HRQoL) in women and men undergoing different dialysis treatments and between patients on home-based and in-centre dialysis.	N=422	Quantitative: Cost and utility analysis
		Questionnaire and register data on health care related costs	Impact of sex on health care related costs and HRQoL
<b>Study IV</b> "The Laundry Bag Project" – unequal distribution of dermatological healthcare resources between women and men	To examine differences in treatments and treatment costs in women and men diagnosed with eczema and psoriasis.	N=586 N=646	Quantitative: Comparisons of treatments and costs
		Records, registers and treatment costs	Impact of gender on treatment distribution and costs

## Study design

All four studies in the thesis had a cross-sectional design, and three of them comprised health care utilisation and treatments costs during one year. *Study IV* included a follow-up. *Study I* investigated total publicly funded health care consumption for the 1.6 million inhabitants in western Sweden (Region Västra Götaland (VGR)). *Studies II* and *III* investigated all adults (>18 years) undergoing dialysis treatment in the VGR and holding a social security number and a home address in Sweden, and who responded to a survey (n=434). *Study IV* investigated all patients referred to the dermatological outpatient department at Danderyd Hospital (DH-Derm) diagnosed with eczema and psoriasis (n=586). For comparison, all patients at another treatment unit (Swedish Psoriasis Association centre, SPA, n=646) were investigated.

## Data collection and management

In *Study I*, data were retrieved from the regional health care database (VEGA) on total publicly funded somatic and psychiatric health care consumption by VGR inhabitants. Data coverage included all care contacts provided by public and private providers within or outside the region. Care contacts were defined as patient visits to primary care, to specialist outpatient care, and care episodes and bed days in inpatient care. Costs for specialist outpatient and inpatient care within the region were assessed using standardised prices in accordance with the region's compensation model. Publicly funded private care and care outside the region were assessed using the actual compensation paid to those providers. Costs for primary care visits were based on the region's average cost for a visit to a medical doctor and the average cost for a visit to other health care personnel.

From the total number of health care contacts, contacts due to reproduction were removed by excluding all visits to maternity and youth clinics and care contacts that had a main diagnosis due to reproduction, according to the International Classification of Diseases, 10th Revision [100]. In the next step, health care received for sex-specific morbidity was excluded. The selected diagnoses represent conditions that are directly associated with sex-specific organs or the reproductive system (for example, breast, cervical and prostate cancer) but do not include conditions that are more *common* in either sex. Furthermore, all disease areas in the International Classification of Diseases were assessed based on a cost perspective and the four most expensive areas were selected for analysis.



In *Studies II and III*, data on social security number, age, sex, and current dialysis modality were collected from the nine hospitals and centres performing dialysis and managing home-based dialysis in the region. The subject's social security number was used to obtain full names and home addresses of the patients from *The Government's Person and Address Records* (Statens Person och Adress Register, SPAR). A questionnaire was sent out to the study population, to which 434 patients responded, yielding a response rate of 70 per cent.

The questionnaire was developed with the main purpose of investigating factors influencing the choice of dialysis modality and was based on discussions with nephrology and dialysis specialists at the Sahlgrenska University Hospital, a representative for the Swedish Kidney Association, researchers in health literacy, and existing knowledge about barriers and facilitators to home-based dialysis [101, 102] and health literacy [103-106]. To measure health-related quality of life (HRQoL), the RAND-36 [107] instrument was included together with common background questions. The final questionnaire comprised 41 questions including 31 sub-items and the 36 questions in the RAND-36 instrument (totalling 107 items). (See the Appendix for all questions included in the survey, their source and how the questionnaire was assessed and tested.)

In order to collect health care-related costs, each patient's social security number was used to retrieve individually generated health care cost data from the regional health care database (VEGA) and for pharmaceuticals, from the regional pharmaceutical database (Digitalis). These databases capture information on all publicly funded health care and pharmaceuticals, utilised and dispensed by the residents in the region. A more detailed description of how the health-care related cost were generated, including travelling and transportation costs, is presented in the Materials and Methods section in *Study III*.

In *Study II*, data from the dialysis centres on age, sex, and current dialysis modality, as well as responses to the questionnaires, were entered into SPSS (version X6.0.2). In *Study III*, data from Study II were moved to the software program SAS 9.4 and 13 variables on health care service utilisation measured as costs were added. The SF-6D algorithm was used on RAND-36 responses to obtain a rating on the six health state domains and the preference-based summary health state index.

In *Study IV*, the computerised medical records system used at DH-Derm was searched in order to determine the number of men and women who had sought

treatment for eczema or psoriasis. The records were searched using the search terms “diagnosis,” “prescription,” “UV treatment” (including different types of UV light), and “bathing”. In the next step, treatment costs were obtained by using codes based on standard calculations of the costs for various treatments, used by the hospital-based dermatology clinics throughout the Stockholm County Council.

In order to make data more compatible to the second treatment unit (SPA), the records search was narrowed to the most homogenous and common diagnosis group within psoriasis, psoriasis vulgaris (plaque psoriasis, ICD code L400). Sex-disaggregated data on the number of patients and UV-treatments were then collected from the second treatment unit (SPA). Lastly, data from the pharmacy were collected concerning medications dispensed for topical skin treatment to patients at DH-Derm and to patients in the entire Stockholm County Council area. Data on patients and treatments were entered into the software program STATISTICA v. 7.0.

## Data analysis and statistics

In *Study I*, the total number of health care contacts and related costs, before and after the exclusion of health care contacts due to reproduction and sex-specific morbidity, were analysed on the basis of average distribution per capita for women and men by age group and level of care. Additionally, the four most expensive disease areas – cancer, cardiovascular disease, diseases of the muscles and joints, and mental health problems – were, after adjustment for sex-specific conditions, analysed on the basis of average cost distribution per capita and level of care for women and men. The chi-square test was used to test for statistically significant differences between women and men.

In *Study II*, as a first step, bi-variable logistic regression analyses were carried out with the dependent variable being the current dialysis modality, dichotomised into in-centre HD and home-based dialysis (the latter including PD and HHD), and independent variables. The independent variables described patient characteristics, medical factors, and information received before dialysis onset.

Information received was described by two variables. The first variable included the number of sources of information on dialysis that the respondent had acquired or received before dialysis onset, and the second variable measured the range and quality of the information and was expressed as an

index. The index included nine items and had a Cronbach's alpha of 0.81 (range 0–1), suggesting satisfactory internal reliability. For a further description of the independent variables, see the Materials and Methods section in *study II*. P values and odds ratios (ORs) with 95 per cent confidence intervals (CIs) were calculated and presented.

In the next step, a logistic regression analysis was carried out with the selected statistically significant variables from the bi-variable analysis as explanatory variables for home dialysis. This analysis was performed on the total dataset and stratified by sex. To further deepen our understanding of how the received information was associated with current dialysis modality, 12 questions regarding information were analysed separately. The Fisher's exact test (two-sided) was carried out to test for statistically significant differences in answers between patients with home dialysis and patients with in-centre HD treatment, as well as differences between women and men. In order to understand which attitudes and perceptions toward home-based dialysis and in-centre HD affect the choice of dialysis method, responses to 19 statements on various aspects of different dialysis modalities were analysed. Again, Fisher's exact test (two-sided) was performed to test for statistically significant differences in answers between patients with home dialysis and patients with in-centre HD treatment, as well as differences between women and men.

In *Study III*, the Fisher's Exact Test and the Mantel-Haenszel Chi Square was used to investigate any differences in dialysis method distribution by gender. To test for statistically significant differences in patient characteristics between patients with different dialysis methods, as well as differences between women and men, the Fisher's Exact Test and the Mantel-Haenszel Chi Square Test were performed. This testing was followed by tests between the same patient groups as in the previous test, regarding the six dimensions of HRQoL and the summary index of SF-6D, using the Mann-Whitney U-Test. In the next step, differences in terms of health care-related costs between the same patient groups were analysed, again using the Mann-Whitney U-Test. Finally, analyses of covariance (ANCOVA) were conducted to identify whether patients' characteristics had a statistically significant impact on the health-care-related costs or on the SF-6D summary index for patients with in-centre HD treatment and patients with home-based dialysis.

In *Study IV*, t-test was used to identify differences regarding the ratio of women and men receiving treatment.

In *Studies I–IV*, all hypothesis testing was evaluated using the 5 per cent statistical significance level.

## Ethics

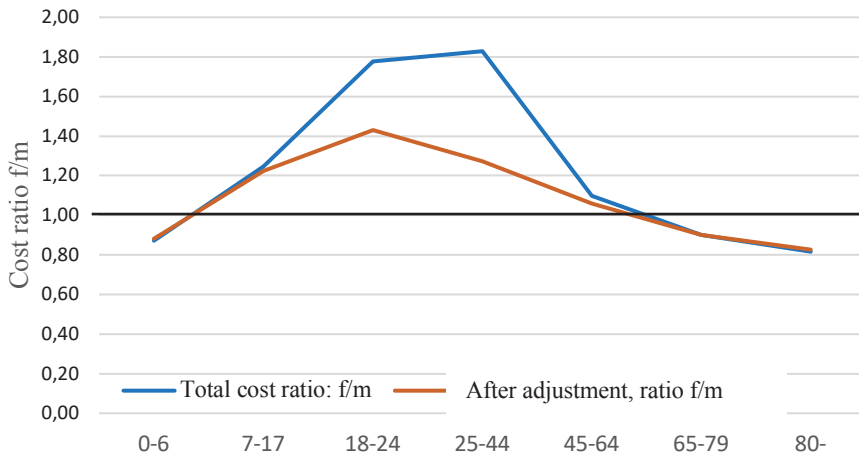
*Studies II* and *III* received ethical approval from the Regional Ethics Committee in Gothenburg (Dnr: 386–15). Before inviting the dialysis patients to the study, participation was confirmed by the nine dialysis centres in the region, to avoid sending questionnaires to deceased individuals or to patients who were no longer on dialysis treatment. An information letter was then sent out to each patient with a description of the study, stating that the patient would within two weeks receive a questionnaire and an invitation to contact the responsible researchers if they had any questions or wished to decline participation. A further information letter was sent out to the participating patients, together with the questionnaire, describing the handling of collected data and stating that their participation was voluntary and could be withdrawn at any time. Moreover, by filling out the questionnaire and sending it back in the enclosed envelope, they were, as stated in the letter, considered to have agreed to participate in the study.

Regarding *Study I*, ethical approval was not required due to the Regional Ethics Committee in Gothenburg since data in the study were aggregated and impossible to link to specific individuals. *Study IV* was carried out as part of a quality assessment in the health care system provided by Stockholm County Council. Owing to the nature of the investigation, ethical approval was not required as communicated by the Regional Ethics Committee at Karolinska Institutet (see 2006/1387-31).

# Results

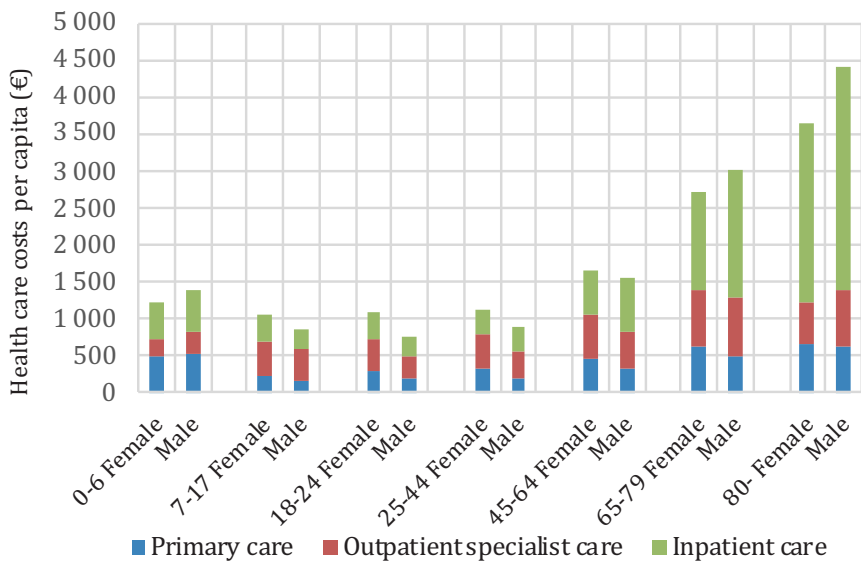
## Study I

The results of *Study I* showed that total per capita cost for health care was 20 per cent higher for women than for men and that the difference was largest for primary care and smallest for inpatient care. When health care consumption was adjusted for reproduction, the cost-difference declined to 10 per cent. After further adjustment for costs associated with sex-specific morbidity, the difference decreased even further, to 8 per cent.



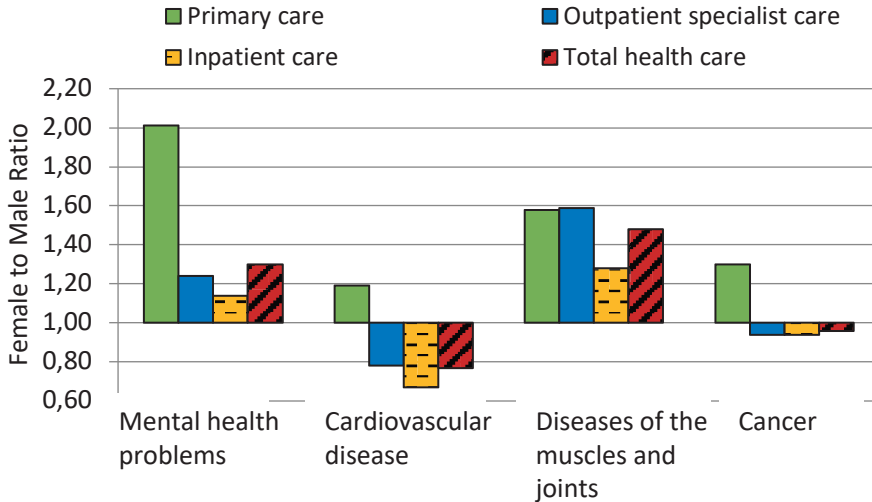
**Figure 2.** Cost ratio, female/male, before and after adjustment for reproduction and sex-specific morbidity, by age group

The total reduction was greatest for women of reproductive age (see Figure 2) and was reflected in all levels of care. The remaining cost difference could be explained by women's substantially higher costs for mental health problems and diseases of the muscles and joints. Women were more likely to receive more accessible and less expensive primary care, while men were more likely to receive specialist inpatient care; the latter was particularly evident in age groups 45 years and older (see Figure 3).



**Figure 3.** Health care costs (€) after adjustment for reproduction and sex-specific morbidity

The finding that women and men receive care at different care levels was also evident in the four most expensive disease areas: cancer, cardiovascular disease, diseases of the muscles and joints, and mental health problems (see Figure 4). Even in cases when total healthcare costs were higher for men (cardiovascular disease and cancer), primary care costs were higher for women.



**Figure 4.** Female-to-male ratio for per capita health care cost by level of care for the most expensive diagnostic areas, after adjustment for sex-specific conditions

## Study II

The results of *Study II* showed that men were more than three times more likely to receive home dialysis if they lived with a spouse compared to if they lived alone – an association that was not observed for women (Table 2). Patients were more likely to have home dialysis if they received pre-dialysis information from three or more sources and, to a greater extent, perceived the information as comprehensive and of high quality. In addition, patients had a greater likelihood of receiving home dialysis if they lived further away from a dialysis centre, and if they were younger.

**Table 2.** Associations between dialysis modality and selected variables

	Women, n=132 Home dialysis, n=43		Men, n=278 Home dialysis, n=84		All, n=410 Home dialysis, n=127	
	OR	95% CI	OR	95% CI	OR	95% CI
<i>Age (years)</i>	0.97*	0.94–0.99	0.99	0.97–1.01	0.98*	0.96–0.99
<i>Living situation</i>						
Living alone (ref)	1		1		1	
Living with spouse	1.46	0.62–3.44	3.08***	1.54–6.14	2.40***	1.43–4.02
<i>Distance to centre/hospital (per 10 km)</i>	1.31**	1.08–1.60	1.21***	1.08–1.35	1.23***	1.12–1.35
<i>Sources of information</i>						
0–2 sources (ref)	1		1		1	
3 or more sources	2.60*	1.10–6.16	1.69	0.96–2.97	1.88**	1.18–3.00
<i>Index of scope and quality of information, Range 18</i>	1.05	0.96–1.15	1.07*	1.01–1.14	1.06*	1.01–1.12

The analyses are based on multiple logistic regression with the dependent variable dichotomised into home dialysis and in-centre HD (the latter is the reference category).

\*\*\*  $P < 0.001$ , \*\*  $P < 0.01$ , \*  $P < 0.05$

In the in-depth analysis of associations between received information and current dialysis method, it became evident that in-centre dialysis patients more often reported a need for more frequent and thorough information on dialysis in general ( $p < 0.05$ ) and more information on PD in particular ( $p < 0.001$ ); they would also appreciate receiving information electronically (for example, by computer, app, or DVD) or as a brochure ( $p < 0.05$ ). Women reported to a lesser extent than men that they had received information about different dialysis modalities and that sufficient information about home HD was given ( $p < 0.05$ ).

Regarding the analysis of which perceptions and attitudes are affecting the choice of dialysis method, the results showed no significant difference between women and men. However, patients on in-centre HD believed to a greater extent than those on home dialysis that the social interaction with staff and fellow patients, together with support and help induced by having in-centre HD and the total freedom from dialysis some days a week, influences modality choice. On the other hand, home dialysis patients believed that the choice is affected by home dialysis as a treatment requiring (i) a lot of space in the home, (i) more personal responsibility, and (iii) implying that the patient is feeling better. Home dialysis patients also perceived home dialysis, to a greater extent, as a burden on family and relatives and as imposing increasing out-of-pocket expenditures.



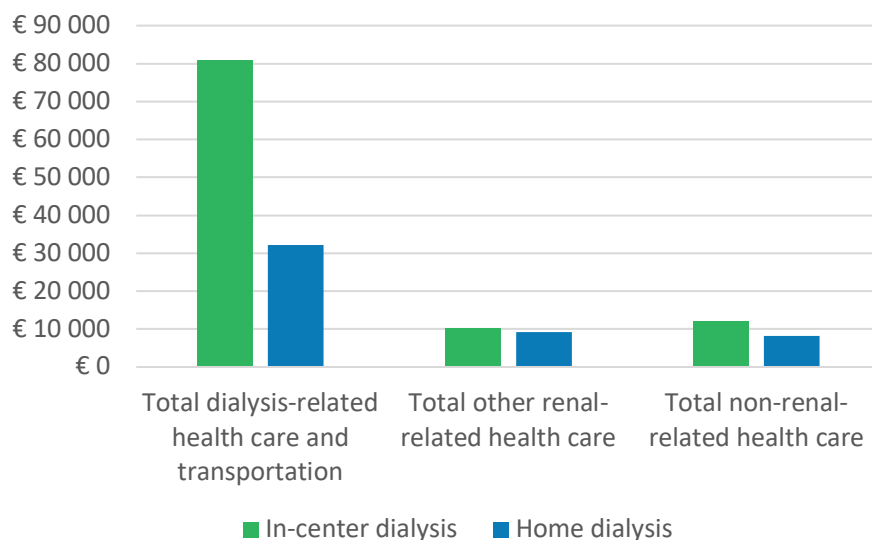
### Study III

Results regarding health-related quality of life (HRQoL) in *Study III* showed that in-centre HD patients reported more pain and a lower social functioning compared to patients receiving home dialysis. Women on in-centre HD treatment reported poorer mental health and lower vitality than corresponding men. Nevertheless, no significant differences in the summary index of health-related quality of life were observed between women and men or between patients on in-centre HD and on home dialysis.

When analysing HRQoL for patients on PD and HHD separately, patients on HHD had a better physical function and a higher summary index of HRQoL compared to patients on PD. Women on HHD had worse social functioning and worse mental health state than corresponding men. However, it should be noted that there were few patients with HHD treatment and they were, on average, 12 years younger and had a higher educational level and a lower mean of co-morbidities than patients on PD.

The total annual dialysis-related health care cost was 2.5 times higher for patients on in-centre HD than for patients on home dialysis (Figure 5). The corresponding number for dialysis- and renal-related health care cost was 2.2.

No significant differences were found between women and men, or between patients receiving PD and HHD regarding total dialysis-related health care costs, total dialysis- and renal-related health care costs, or overall health care costs. The only cost items that demonstrated significant differences were attributed to pharmaceuticals within home dialysis. Patients on HHD revealed higher costs for dialysis-related pharmaceuticals than patients on PD, and men on home dialysis exhibited higher costs for other renal-related pharmaceuticals than women.



**Figure 5.** Annual average health care related costs, in in-centre and home dialysis patients, 2015

The analyses of covariance (ANCOVA) showed no influence of mean age, sex, educational level, native language, living situation (living alone or together) or mean number of co-morbidities on the dialysis-related health care costs or the dialysis- and renal-related health care costs. Nevertheless, the mean number of co-morbidities had a statistically significant impact on the SF-6D summary index, but differences between in-centre and home dialysis remained insignificant.

The public health care provider can expect an annual gross cost saving of €48,700 for every patient who chooses a home-based dialysis treatment over in-centre dialysis treatment.

## Study IV

The result of *Study IV* showed that as many women as men with a diagnosis of eczema or psoriasis sought treatment at DH-Derm (Table 3). Bathing treatment was administered 456 times to these patients and whole-body ultraviolet radiation (UV treatment) was administered on 2,140 occasions. A substantially larger group of men (63 per cent) than women (37 per cent) received whole-body UV treatment for psoriasis or eczema ( $P < 0.0001$ ). No apparent gender differences regarding the severity of symptoms could be identified from the patient records for these diagnoses.

**Table 3.** Treatment of women and men with eczema and psoriasis, DH-Derm, 2003

	Patients diagnosed with eczema, n (%)	Patients diagnosed with psoriasis, n (%)	Patients diagnosed with eczema or psoriasis, n (%)	Patients with bathing treatment, n (%)	Patients with UV-treatment, n (%)
Women	134 (52)	157 (48)	291 (50)	46 (52)	47 (37)***
Men	126 (48)	169 (52)	295 (50)	42 (48)	79 (63)
Total	260 (100)	326 (100)	586 (100)	88 (100)	126 (100)

\*\*\* =  $p < 0.0001$  regarding treatment differences between women and men.

When the treatments for men and women with eczema and psoriasis were priced, it was found that women's treatment costs were US\$ 31,750 less than men's treatment costs, equivalent to 22 per cent of the treatment budget.

In order to make the treatment figures comparable with other clinics performing UV treatment for psoriasis, analyses were conducted on the number of treatments per individual diagnosed with psoriasis vulgaris, the numerically largest diagnosis group. Corresponding data were collected from a second psoriasis treatment unit, SPA (Table 4).

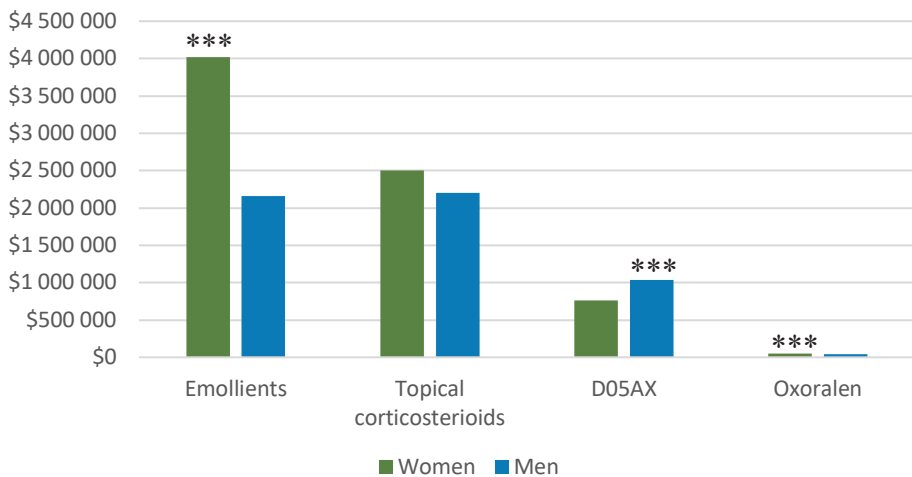
**Table 4.** Ultra-violet radiation (UV) treatment of women and men with psoriasis, DH-Derm and SPA, 2003

		Number of individuals	%	Number of treatments	Number of treatments/patient (mean value)	%
<i>DH-Derm</i>	Women	38	44	768	22.2	38*
	Men	48	56	1244	25.9	62
<i>SPA</i>	Women	273	42	5369	19.6	36***
	Men	373	58	9712	26.0	64

\* =  $p < 0.05$ , \*\*\* =  $p < 0.00001$  regarding treatment differences between women and men.

Data from DH-Derm and SPA showed that men received significantly more UV treatment for common psoriasis than women.

Prescriptions for self-care topical treatment were issued to all patients diagnosed with psoriasis or eczema. A straightforward assumption was that patients who did receive self-care as a stand-alone treatment performed more self-care with topical skin medications than those who received treatment in the clinic. Data from Apoteket were analysed concerning medications dispensed for topical skin treatment for patients at DH-Derm and for the Stockholm County Council as a whole (Figure 6), with similar results.



D05X is a topical treatment for psoriasis. Oxoralen are tablets taken in connection with a particular UV-treatment (PUVA). \*\*\*=  $p < 0.001$

**Figure 6.** Dispensed prescriptions in Stockholm County Council in \$US, 2003

The total value of medication dispensed to women was greater than the total value of medication dispensed to men ( $P < 0.001$ ), and the largest sex difference was present in emollients.

The results of this investigation were discussed with the staff at DH-Derm and a follow-up regarding UV treatments for psoriasis patients was carried out one year later. The result from the follow-up did not show statistically significant treatment differences between women and men, which is at odds to the previous year.

# Discussion

## *Defining gender equality and equity in the context of health care*

The opening paragraph in the Swedish health and medical services Act (Law 1997:142), together with the ethical platform for health care priority-setting, constitute the fundamental ethical principles on which the Swedish health care system is based. The first ethical principle refers to non-discrimination in the health care sector; that is, an equality principle. The second refers to need and solidarity; that is, an equity principle. The third (not included in the formulation of the Law 1997:142) stresses that cost-effectiveness should be considered.

As the present thesis explores women's and men's health care utilisation from a cost perspective, it is important to clarify what these principles mean from a sex/gender perspective in a Swedish health care context.

When considering both international and Swedish standpoints regarding the concepts of *gender equality* and *gender equity* in health and health care, it becomes clear that the content of both concepts is essential. When it comes to justice and fairness between women and men receiving health care, the concepts and definitions need to be comprehensive *and* have the ability to cover the complexity of the issue. Based on the established concepts of equality and equity, and with the presented standpoints, I recommend the content of both concepts, as suggested in boxes C and D in Table 5.

**Table 5.** Gender equality and equity in the context of health care provision in Sweden

<p><i>A Equality</i></p> <p>Ensure that people in equivalent circumstances are treated the same (e.g., in relation to geographical location or suffering from the same condition).</p> <p><i>Gender equality is included in Equality.</i></p>	<p><i>B Equity</i></p> <p>Ensure that people (or communities) who are in unequal positions/circumstances are treated differently, in a way that is commensurate with their relative disadvantage (e.g., in relation to disabilities or a worse health due to socioeconomic position).</p> <p><i>Gender equity is included in equity but represents a distinct position.</i></p>
<p><i>C Gender equality</i></p> <p>Ensure that women and men and other sexualities in equivalent circumstances (i.e., when they have</p>	<p><i>D Gender equity</i></p> <p>Ensure the provision of different treatment in accordance with biological sex-differences (e.g.,</p>

<p>equivalent needs and the biological sex differences are irrelevant) are treated the same.</p>	<p>in relation to reproduction and sex-specific diseases),</p> <ul style="list-style-type: none"> <li>- and sex-adjusted treatment (e.g., in relation to areas where knowledge about both (all) sexes are essential for a successful outcome</li> <li>- <i>Gender equity</i> also implies that medical research and the health care sector prioritises health problems and diseases that occur, or mainly occur in one of the sexes, to the same extent as other medical problems.</li> </ul>
--	---

### ***Cost differences in health care utilisation between women and men***

There are similarities and differences between women's and men's health care utilisation. *Study I* revealed that, at an overarching regional level, women annually consume 20 per cent more health care resources than men. However, much of these additional costs relate to women's health care associated with reproduction. Hence, they should conceptually be seen as a sex specific need referring to the gender equity concept. From an economic perspective, this consumption is a matter of investing in new society members, as opposed to a cost that emanates from treatment of disease; that is, a distinct case of human capital investments. A further share of women's additional costs was related to their greater health care utilisation due to other sex-specific conditions than reproduction, consequently also referring to the gender equity concept (*I*). The remaining share could be explained by women's substantially larger costs for mental health problems and diseases of the muscles and joints (*I*). On the other hand, men exhibit higher health care costs for cancer and cardiovascular disease in relation to women (*I*). It should also be noted that chronic kidney disease, which is the main reason why renal replacement therapy is needed, is clearly linked to cardiovascular disease [97]. *Studies II* and *III* revealed that two-thirds of patients receiving dialysis treatment were men, which implies higher *total* health care-related cost for dialysing men. In contrast, when the average annual health-care-related costs for dialysis treatment were analysed through stratifying by sex (*III*), no cost differences between women and men were observed. This result should conceptually be referred to as *gender equality*, as it demonstrated an almost gender equal distribution of publicly funded health care resources between women and men with the same treatment method.

The treatment cost for eczema and psoriasis at the outpatient specialist clinic in Stockholm exhibited substantially greater cost for men than for women, with no apparent clinical difference in symptom severity between the sexes (*IV*).

Concurrently, higher costs for topical skin medications were noted for women than for men. Accordingly, these results demonstrate gender in-equality in the distribution of public health care resources. Interestingly, discussions about the disclosed findings among the clinical staff led to the differences disappearing at a follow-up one year later regarding-UV treatment in patients with common psoriasis (*IV*). This demonstrates the importance of knowledge and attention of staff regarding unequal treatment patterns, thus leading to rather rapid changes.

Another important result refers to cost differences between women and men in terms of utilised level of care (*I*). Women are more likely to consume less expensive primary care, while men are more inclined to consume more expensive specialist care, particularly in older age groups. This pattern is also evident in the four most resource demanding diagnostic areas, where women had a higher share of primary health care costs in all four areas (cancer, cardiovascular disease, diseases of the muscles and joints, and mental health problems) in relation to their total costs for these diagnostic areas. Notably, this was even true regarding cardiovascular disease and cancer, where men exhibited higher total costs. Given the cost differences between women and men within the four most resource demanding diagnostic areas, and the utilised level of health care, more in-depth analyses are needed in order to assess the differences from a *gender equality* and *equity* perspective.

### *Informal care*

The treatment differences for eczema and psoriasis (*IV*) implied that the outpatient specialist clinic funded treatments of men's skin diseases to a greater extent than women's, whilst women were more inclined to self-care in their home. Additionally, men who underwent dialysis treatment were three times more likely to receive home-based dialysis if they lived with a spouse compared to if they lived alone – an association that was not observed for women (*II*). Accordingly, results showed that home-based dialysis was substantially less costly than in-centre HD treatment (*III*). This suggests that women's provision of support and informal care towards men on dialysis enable them to choose a dialysis treatment that saves a lot of publicly funded health care resources. These findings are consistent with traditional gender norms, implying that women in general provide more informal care and support to family members than men do [108, 109], and research findings indicating that men benefit more from informal care than women [110].

Women's contribution of informal care (in the present studies, self-care and partner care) are unrecognised and unaccounted for in the Swedish National

Accounts and gross domestic product (GDP). As such, it can be considered as a *hidden subsidy* to the health care sector that should be recognised and valued [111]. A health economic evaluation from a societal perspective comprises both measurement and valuation of informal care. However, this does not imply that the measured value of informal care is included in the National Accounts and gross domestic product (GDP).

Researchers have estimated the financial value of women's contributions of unpaid *health care* work to 2.35 per cent of global gross domestic product (GDP) [111]. The estimation was based on data from 32 countries, accounting for 52 per cent of the world's population in 2010. The total value of women's unpaid care work is estimated to be considerably higher [111].

### *The health care utilisation approach*

The health care service utilisation approach presented earlier in this thesis (see Figure 1; Liss 1990), provides a conceptual framework for analyses of the included studies (*I – IV*) and illustrates the dynamics behind health care utilisation [16]. The figure depicts how the three concepts of health care need, demand and supply overlap each other and shape the actual health care utilisation; that is, areas B and G (Figure 7). In situations when an individual's demand for health care correspond to the health care provider's recommendation of health care – that is, the supply – it leads to utilisation. It is difficult to estimate the size and proportions of the different areas in the figure except for the size of the actual health care utilisation (area B and G). The proportions of the remaining areas, especially those involving health care need, are mainly an empirical matter.

The sex and gender aspects of the determinants of health are expected to affect the need for health care; that is, the size of women and men's area 1 (Figure 7). Gender differences in need and barriers to seek health care are expected to affect the demand of health care; that is, women and men's size of area 2. Further, differences in the health care provider's recommendation – i.e. the structure of the supply side – are expected to affect the health care available and treatments provided to women and men, area 3.

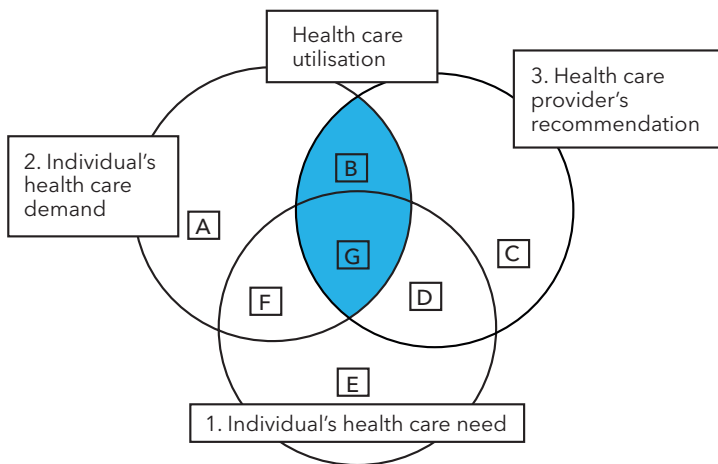
*Study I* comprises visits and costs occurring in the total area of B and G for the population in VGR. Based on the result in this study, all three areas in the model are larger for women than for men, mainly depending on health care needs in connection with reproduction and sex-specific morbidity, together with gender differences in the demand of health care for diseases of the muscles and joints and mental health problems. However, gender differences



in the supply side were also evident regarding the level of health care provided to women and men.

*Studies II, III and IV* can mainly be seen as sub-parts of area B and G. In *Study II* the patient's choice of dialysis method (that is, demand for treatment) was affected by various factors including gender relations; that is the informal care provided by spouses. The informal care could be referred to area E, where individual's health care needs are present, however met by informal care in contrast to formal health care provision. The result in *Study III* exhibits no gender differences regarding treatments and treatment costs. Nevertheless, the proportion of in-centre dialysis treatments that could be replaced by home dialysis without social and medical impairments, could be referred to area B, an area described by Liss [16] as inefficient use of resources i.e. "no providers recommendation without available resources".

In *Study IV* the health care provider (i.e. the supply side) revealed a gender-biased treatment distribution, which meant that men received more treatments for two common skin diseases, where no gender differences regarding the severity of the illnesses could be observed. Consequently, women compensated for this gender bias with informal self-care (once again referring to area E where health care needs are met by informal care, i.e. self-care).



**Figure 7.** The health care service utilisation approach (Liss, 1990) [16]

Area F refers to a situation where the individual has a need and demand for health care but there is no provider's recommendation (i.e. no supply). In relation to sex and gender, one could speculate that such a situation may occur due to biases in the health care system and a skewed distribution of investing

in health research [8, 111]. Research indicates a slower recognition of health problems particularly affecting women, which will have consequences for the level of knowledge, priorities and implementation of treatments [8, 111-114]. In certain areas, this may also apply to health problems particularly affecting men, such as the research and ongoing discussion regarding prostate screening.

Johnsson et al. suggest that parts of women's actual higher health care utilisation rates might reflect frustration over inadequate treatment and ineffective care, for example regarding women who repeatedly seek treatment for chronic pain [14]. This phenomenon could probably, to some extent, be related to the finding in *Study I*, which showed that women had a substantially higher cost for diseases in muscles and joints, generally associated with pain [115].

Area D refers to a situation where the individual's need for health care is present and the health care providers recommend treatment, but the individuals are not demanding it. This situation can be understood as barriers to seeking health care. Men are considered to be more reluctant than women to seek health care, except in cases of acute illness [57, 61]. On the other hand, women's substantially greater use of reproduction-associated care already at a young age, which largely occurs within primary care, as shown in *study I*, might make it easier for them to also seek health care for other reasons. Therefore, women can be considered to be socialised to seek health care to a greater extent than men. Efforts to eliminate barriers that prevent men from investing in their health and seeking primary care could reduce future morbidity and costs for specialist care.

Collectively, on the basis of the included studies it is clear that the size of the areas and their overlapping (Figure 7) differ between women and men. In terms of the sex and gender determinants of health to health care utilisation, the sex-disaggregated health care service utilisation approach can help determine where in the process differences between women and men occur.

### *To achieve cost-savings in dialysis treatment*

The results of *Study III* show that cost savings could be realised if more dialysis patients and pre-dialysis patients suitable for home-based dialysis would be supported to choose these less resource-demanding dialysis methods. Hence, to realise a resource allocation where no one is made worse off – instead, someone else is gaining – by making resources available for other purposes. To reach this goal, the results in *Studies II* and *III* showed that conscientious measures on both a more overarching, as well as at a patient interaction level,

need to be taken into consideration to reduce barriers to home-based dialysis compared to in-centre HD. *First*, an evaluation and probably alteration of financial incentives and policies in order to promote home dialysis. *Second*, ensuring all patients and their relatives repeated, comprehensive, high-quality information, including considerations to use new ways to dispense information, such as electronically. It is also important that the information and support is adapted to the specific needs of different patients, patient groups and their relatives, taking gender into account. As the results in *Study II* indicated, women experienced to a lesser degree than men that they had received sufficient information about different dialysis methods, especially home HD. Further, as lonely living patients or relatives of pre-dialysis patients, men may require additional information and support in order to facilitate them or their spouse to choose a home-based dialysis method. A suggestion is to invest in a health-literate health care organisation [116, 117], characterised by the ability to meet the needs of populations with varying health literacy skills. (Health literacy is often defined as an individual's ability to access, understand, appraise, and apply health-related information [118].)

The results generally suggest the need for more support for home-dialysing patients and their relatives, including financial support to compensate for increased out-of-pocket expenditures associated with home dialysis, as well as increased social interaction, which according to patients on in-centre HD proved to be a core aspect in the choice of in-centre HD.



# Conclusion

This thesis establishes the following conclusions, from an overarching regional level to an individual patient level.

- In Sweden, there are substantial differences between women's and men's health care consumption at an overall level, and within various disease areas and conditions, and in terms of utilised level of care.
- Many of women's additional costs are related to health care contacts associated with reproduction and should consequently be seen as a specific issue because they are primarily a question of investing in new society members and not costs related to disease treatment, which makes them a distinct form of human capital investment.
- It is essential to take the gender distribution of informal care, including self-care and partner care, into account when analysing women's and men's health care utilisation, since informal care represent a hidden, potential gender biased, subsidy to the health care sector.
- There are a number of factors associated with home-based dialysis, such as recurrence, scope and quality of pre-dialysis information and cohabitation (the latter only concerns men). Likewise, social interaction, support and out-of-pocket expenditures affect the choice of the dialysis method.
- Total annual dialysis-related health care cost is more than twice as high for patients on in-centre HD than for patients on a home-based dialysis method in western Sweden (VGR). There are no cost differences between women and men or between the home-based methods, peritoneal dialysis and home haemodialysis.
- To detect differences in health care utilisation for women and men, it is important to analyse data disaggregated by sex.



## Future perspectives

It is important to disaggregate and analyse public health care spending by gender, preferably together with other sociodemographic factors, in order to enable transparency and accountability of the health care sector. Likewise, the scope and gender distribution of unpaid care work must concurrently be analysed and addressed. Given the prevailing situation of limited health care budgets, such analyses are important to ensure that women and men receive gender equal and equitable health care services, adhering to the ethical principles on which the Swedish health care system is based, and to avoid (an increasing bulk of) gender biased informal care.

Health care cost related to reproduction is a special form of health care that comprises a large share of women's additional health care costs compared to men. Consideration should be made to set up a specific budget line, within the health care budgets, that covers health care costs for investments in new society members. This distinct form of human capital investment includes both public and parental expenses, as well as unpaid care work and physical hardship for mothers. Hence, the health-economic toolbox should be used to assess the total societal cost of investing in new society members.

Moreover, women's substantially greater use of reproduction-associated care at a young age, which largely occurs within primary care, can be viewed as a form of training in seeking health care. Apparently, this does not apply to men. Efforts to make it easier for men to invest in their health by seeking primary care, and preferably to do so earlier, could reduce future morbidity and costs for specialist care. To achieve this, consideration should be made to support schools and youth clinics to engage in boys' and men's health to a greater extent. Furthermore, more research is needed that compares women's and men's health-care-seeking behaviour for different health conditions.

Another important issue is to determine why women are overrepresented regarding mental health problems and diseases of the muscles and joints, which often also occur as co-morbidities. Efforts and interventions are needed to decrease these distressing and costly conditions by providing good access to health care services with high-quality treatment. Additionally, the causes of these illnesses often seem to be related to living conditions, including work and family life, which also need to be addressed.

Regarding the importance of information and support to dialysis and pre-dialysis patients and their relatives, it is evident that there is room for improvement in order to boost patient empowerment with increased use of home dialysis. The greater the number of patients that use home dialysis, the more savings of public resources will occur. The implementation of strengthened information and support strategies must also be evaluated capturing consequences for patients and their relatives.

In the light of the recently adopted gender equality goal in Sweden; *gender equality in health and care*, it has become crucial to understand what this goal actually implies in the context of health care utilisation. Although the issue is complex, progress has been made regarding the clarification of the concepts of gender equality and equity in health care. This is important given that the ethical principles on which the Swedish health care system is based, rest on principles of equality and equity. There is unfinished work still to be done regarding, for example, sex and gender in relation to the priority dimension of the Medical Services Act and the ethical platform for health care priority-setting, demanding that different health care needs are to be assessed, analysed and ranked.



# Acknowledgement

Jag vill rikta ett stort tack till alla som hjälpt mig på vägen i avhandlingsarbetet, särskilt till min huvudhandledare Krister Järbrink som med stor kunskap och vänlighet alltid stöttat, väglett och varit öppen för frågor och diskussioner.

Ett varmt tack till mina bi-handledare Gunilla Krantz, som med stor energi bistått med värdefull erfarenhet och kunskap och givit många uppmuntrande ord, och Sylvia Määttä som möjliggjorde avhandlingsarbetet och bidrog med betydande kompetens.

Ett stort tack till mina medförfattare; Börje Haraldsson, Lena Mårtensson, Filippa Nyberg och Birgitta Evengård.

Jag är tacksam för gedigen statistisk hjälp från Max Petzold, Sara Gustavsson, Mattias Molin och Henrik Albrektsson. Tack för alla datauttag ur VEGA som gjordes av Mikael Kjerfve och för hjälpen med strukturen för enkätsvaren i SPSS av Robin Fornazar.

Anna Månsdotter, Annette Lennerling och Ingvar Karlberg gav goda och framåtsyftande råd i samband med min halvtidskontroll.

Ett varmt tack till kollegorna på EPSO och till forskningsgrupperna jag deltagit i och som med varm och kunnig hand letts av Gunnel Hensing.

Jag vill tacka alla kollegor i doktorandgruppen som varit ett välbehövligt vattenhål för erfarenhetsutbyte, stöttning och trevlig samvaro under doktorandtiden.

Marianne Carlberg och övrig personal inom dialysvården i regionen som hjälpt till att skapa dialysprojektet, och alla dialyspatienter som delade med sig av sina erfarenheter av dialys.

Tack kollegor på Kunskapscentrum för jämlik vård och mina nya kollegor på Jämställdhetsmyndigheten för bra och trevligt samarbete och för visad förståelse och intresse för mitt doktorandarbete.

Jag vill tacka Västra Götalandsregionen för möjligheten att bedriva doktorandstudier och Jämställdhetsmyndigheten för att ge mig tid att bli klar med min avhandling.

Jag vill tacka Agneta Stark som väckte mitt intresse för ”gender budgeting analyser” och Anna Klerby, som jag utvecklat detta arbete med.

Ett stort och varmt tack till min familj som oförtröttligt stöttat och uppmuntrat mig och som stått ut med att jag behövt läsa och skriva fast det finns så mycket annat roligt att göra.

Min livskamrat Peter, som alltid har trott på mig och vars kloka, varma och erfarna stöd burit mig vidare. Mina underbara barn Mingo, Charlotte, Anton och Alexander med sina parter och lilla nytilskottet Amelie. Mina barns far Wilfried som tog stort ansvar för familjen i början av min studietid. Mina härliga bonusbarn Olof, Kristin och Björn och min oförtröttliga svärmor Dagny som lagat mat åt oss när jag varit nedgrävd i avhandlingsarbete.

Mina kära föräldrar, Hilke och framlidne Christian, och mina goda bröder Andreas, Erik och Markus. Min kära faster Michaela och min enastående bror Walter vars livsstöd är ovärderligt. Walters fina familj; Cilla, William, Lily och Leo.

# References

1. Hammarstrom A, Johansson K, Annandale E, Ahlgren C, Alex L, Christianson M, et al. Central gender theoretical concepts in health research: the state of the art. *Journal of epidemiology and community health*. 2014;68(2):185-90.
2. Hovelius B, Johansson EE. *Kropp och genus i medicinen*. Lund: Studentlitteratur; 2004.
3. Mansdotter A, Lindholm L, Ohman A. Women, men and public health-how the choice of normative theory affects resource allocation. *Health policy (Amsterdam, Netherlands)*. 2004;69(3):351-64.
4. Hirdman Y. *Genussystemet : reflexioner kring kvinnors sociala underordning*. Sverige: *Genushistoria : en historiografisk exposé*; 1988.
5. SCB. 30 största yrkena 2016 [Available from: <https://www.scb.se/hitta-statistik/statistik-efter-amne/arbetsmarknad/sysselsattning-forvarvsarbete-och-arbetstider/yrkesregistret-med-yrkesstatistik/pong/tabell-och-diagram/30-storsta-yrkena/>].
6. Harding SG. *The science question in feminism*. Milton Keynes: Open University Press; 1986.
7. De los Reyes P. Intersektionalitet : kritiska reflektioner över (o)jämlighetens landskap. Mulinari D, editor. Malmö: Liber; 2005.
8. Sen G, Östlin P. Gender inequity in health: why it exists and how we can change it. *Global Public Health*. 2008;3(sup1):1-12.
9. Socialstyrelsen. *Vård och behandling av personer med intersexuella tillstånd Kartläggning av det tidiga omhändertagandet 2017* [Available from: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20474/2017-1-24.pdf>].
10. Dhejne C, Öberg K, Arver S, Landén M. An Analysis of All Applications for Sex Reassignment Surgery in Sweden, 1960–2010: Prevalence, Incidence, and Regrets. *Archives of Sexual Behavior*. 2014;43(8):1535-45.
11. Tanzi V. Fundamental Determinants of Inequality and the Role of Government. *IMF Working Papers*. 1998;98(178):1.
12. Klerby A, Osika I. The gender mainstreaming of public budgets. In: Lindholm K, editor. *Gender Mainstreaming in Public Sector Organisations*. Lind: Studentlitteratur; 2012.
13. Carlgren F. Offentliga sektorns utgifter *EkonomiFakta: Svenskt Näringsliv*; 2018 [July 2018]. Available from:

- <https://www.ekonomifakta.se/Fakta/Offentlig-ekonomi/Offentlig-sektor/Offentliga-sektorns-utgifter/>.
14. Jonsson PM, Schmidt I, Sparring V, Tomson G. Gender equity in health care in Sweden--minor improvements since the 1990s. *Health policy* (Amsterdam, Netherlands). 2006;77(1):24-36.
  15. Kuhlmann E, Annandale E. *The Palgrave Handbook of Gender and Healthcare* (2nd ed.). Great Britain: Palgrave Handbooks; 2012.
  16. Liss P. Health care need. Meaning and Measurement [Thesis]. Linköping, Tema, University: Motala Grafiska; 1990.
  17. UN. Platform for Action, Fourth World Conference on Women United Nations entity for Gender Equality and the Empowerment of Women 1995 [Available from: <http://www.un.org/womenwatch/daw/beijing/platform/>].
  18. Austen S, Costa M, Sharp R, Elson D. Expenditure Incidence Analysis: A Gender-Responsive Budgeting Tool for Educational Expenditure in Timor-Leste? *Feminist Economics*. 2013;19(4):1-24.
  19. Elson D. Budgeting for Women's Rights New York: UNIFEM; 2006 [Available from: <https://www.internationalbudget.org/wp-content/uploads/Budgeting-for-Women%E2%80%99s-Rights-Monitoring-Government-Budgets-for-Compliance-with-CEDAW.pdf>].
  20. Khan Z, Burn N. *Financing for Gender Equality: Realising Women's Rights through Gender Responsive Budgeting*. New York: Springer Nature, Palgrave Macmillan; 2017.
  21. Klatzer E, Schlager C. The Big Picture Makes a Big Difference: Taking into Account Changed Framework Conditions for Budgetary Policies at European Level in Gender Responsive Budgeting. *Politica Economica/Journal of Economic Policy*. 2015;31(2):135-53.
  22. Krinickiene E. A Model For Assessing The Gender Aspect In Economic Policy. *Business, Management and Education*. 2015;13(1):46-63.
  23. O'Hagan A. Favourable Conditions for the Adoption and Implementation of Gender Budgeting: Insights from Comparative Analysis. *Politica Economica/Journal of Economic Policy*. 2015;31(2):233-52.
  24. Ortiz I, Cummins M. Austerity Measures in Developing Countries: Public Expenditure Trends and the Risks to Children and Women. *Feminist Economics*. 2013;19(3):55-81.
  25. Downes R. Gender budgeting in OECD countries. *Oecd Journal On Budgeting*. 2017;16(3):71.
  26. Government Offices of Sweden, *Jämställdhetsbudgetering 2016* [Available from: <https://www.regeringen.se/regeringens-politik/jamstallldhet/jamstallldhetsbudgetering/>].
  27. Stotsky J. Gender Budgeting: Fiscal Context and Current Outcomes. *IMF Working Papers*. 2016;16(149):1.

28. Elson D. Male Bias in Structural Adjustment. In: Haleh Afshar CD, editor. Women and Adjustment Policies in the Third World New York: St. Martin's Press; 1992. p. 46-68.
29. Elson D. Gender Awareness in Modeling Structural Adjustment. World Development. 1995;23(11):1851-68.
30. WHO. Strategy on women's health and well-being in the WHO European Region: WHO regional office for Europe; 2016 [Available from: [http://www.tuseb.gov.tr/tacese/yuklemeler/ekitap/Womens%20health%20and%20well-being%20in%20Europe%20beyond%20the%20mortality%20advantage%20\(2016\).pdf](http://www.tuseb.gov.tr/tacese/yuklemeler/ekitap/Womens%20health%20and%20well-being%20in%20Europe%20beyond%20the%20mortality%20advantage%20(2016).pdf)
31. WHO. Strategy on the health and well-being of men in the WHO European Region: WHO regional office for Europe; 2018 [Available from: [http://www.euro.who.int/\\_data/assets/pdf\\_file/0003/378165/68wd12e\\_MensHealthStrategy\\_180480.pdf](http://www.euro.who.int/_data/assets/pdf_file/0003/378165/68wd12e_MensHealthStrategy_180480.pdf)
32. Culyr A, Newhouse JP. Handbook of health economics. Volume 1A. North-Holland: Elsevier Science; 2000.
33. Williams A. Health economics: the cheerful face of the dismal science. In: Williams A, editor. In Health and Economics. London: Macmillan; 1987.
34. Acheson D. Independent Inquiry into Inequalities in Health Report The Stationery Office 1998 [Available from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/265503/ih.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/265503/ih.pdf)
35. Marmot M, Friel S, Bell R, Houweling TA, Taylor S. Closing the gap in a generation: health equity through action on the social determinants of health. Lancet (London, England). 2008;372(9650):1661-9.
36. Dahlgren, Whitehead. Social Determinants of Health Model of Health [Available from: [www.nwci.ie/download/pdf/determinants\\_health\\_diagram.pdf](http://www.nwci.ie/download/pdf/determinants_health_diagram.pdf).
37. Payne S, Doyal L. Re-visting Gender Justice in Health and Healthcare. In: Kuhlmann E, Annandale E, editors. The Palgrave Handbook of Gender and Healthcare. 2nd ed. Great Britain: Palgrave Handbooks; 2012.
38. Hawkes S, Buse K. The Global Health 50/50 Report: How gender-responsive are the world's most influential global health organisations?'. London: University College London Centre Gender and Global Health; 2018.
39. Altemus M. Sex differences in depression and anxiety disorders: Potential biological determinants. Hormones and behavior. 2006;50(4):534-8.

40. Lorentzon M, Cummings S. Osteoporosis: the evolution of a diagnosis. *Journal of internal medicine*. 2015(277):650–61.
41. Poon S, Goodman SG, Yan RT, Bugiardini R, Bierman AS, Eagle KA, et al. Bridging the gender gap: Insights from a contemporary analysis of sex-related differences in the treatment and outcomes of patients with acute coronary syndromes. *American heart journal*. 2012;163(1):66-73.
42. Mellner C, Krantz G, Lundberg U. Symptom reporting and self-rated health among women in mid-life: the role of work characteristics and family responsibilities. *International journal of behavioral medicine*. 2006;13(1):1-7.
43. Schenck-Gustafsson K, DeCola P, Pfaff D eae. *Handbook of clinical gender medicine*. Basel: Karger; 2012.
44. SOU 2014:81. Yrke, karriär och lön – kvinnors och mäns olika villkor på den svenska arbetsmarknaden, Forskningsrapport till Delegationen för jämställdhet i arbetslivet.
45. Arbetsmiljöverket. Kvinnors och mäns arbetsvillkor – betydelsen av organisatoriska faktorer och psykosocial arbetsmiljö för arbets- och hälsorelaterade utfall kunskapssammanställning, Kunskapssammanställning, Rapport 2016:2.
46. Arbetsmiljöverket. En vitbok om kvinnors arbetsmiljö, Rapport 2017:6.
47. SBU-rapport nr 223. Arbetsmiljöns betydelse för symtom på depression och utmattningssyndrom. En systematisk litteraturoversikt. Statens Beredning för medicinsk Utvärdering. 2014.
48. Vingård E. En kunskapsöversikt Psykisk ohälsa, arbetsliv och sjukfrånvaro. Forte Forskningsrådet för hälsa, arbetsliv och välfärd; 2015.
49. Toivanen S, Gisselmann M, Lindfors P. Kön, genus och hälsa: socioekonomiska skillnader i hälsa bland kvinnor och män. Rapport: Stockholms Universitet, s. 1–40; 2012.
50. Försäkringskassan. Kvinnors sjukfrånvaro En studie av förstagångsföräldrar. Rapport 2014:14.
51. Vision. Kvinna och chef – då är du också projektledare hemma. 2014.
52. Angelov N, Johansson P, Lindahl E, Lindström EA. Kvinnors och mäns sjukfrånvaro. IFAU rapport 2011:2; 2011.
53. SBU, Occupational Exposures and Back Disorders 2014 [Available from: [http://www.sbu.se/upload/Publikationer/Content1/1/Occupational\\_Exposures\\_Back\\_Disorders.pdf](http://www.sbu.se/upload/Publikationer/Content1/1/Occupational_Exposures_Back_Disorders.pdf)].
54. Lundberg U, Krantz G, Berntsson L. ”Total arbetsbörda, stress och muskelvärk i ett genusperspektiv”. *Socialmedicinsk tidskrift*. 2003; 3:245–54.

55. Wu V, Huff H, Bhandari M. Pattern of physical injury associated with intimate partner violence in women presenting to the emergency department: a systematic review and meta-analysis. *Trauma, violence & abuse*. 2010;11(2):71-82.
56. Lövestad S, Löve J, Vaez M, Krantz G. "Prevalence of intimate partner violence and its association with symptoms of depression; a cross sectional study based on a female population sample in Sweden". *BMC public health*. 2017;17(1):335.
57. Courtenay WH. Constructions of masculinity and their influence on men's well-being : a theory of gender and health. *Social Science & Medicine*. 2000;50(10):1385-401.
58. Farrimond H. Beyond the caveman: rethinking masculinity in relation to men's help-seeking. *Health (London, England : 1997)*. 2012;16(2):208-25.
59. Galdas PM, Cheater F, Marshall P. Men and health help-seeking behaviour: literature review. *Journal of advanced nursing*. 2005;49(6):616-23.
60. O'Brien R, Hunt K, Hart G. 'It's caveman stuff, but that is to a certain extent how guys still operate': men's accounts of masculinity and help seeking. *Social Science & Medicine*. 2005;61(3):503.
61. SKL. Vården i siffror, Personer med undvikbar slutenvård [Available from: <https://vardenisiffror.se/indikator?measures=ab52b49f-889e-47f7-adf2-44e3a8323581&measures=c2e6e2d4-78b5-4b48-9bcc-eb8cc8a91645&metadatameasure=e36a09de-4578-4081-bdcd-850cc14407da&relatedmeasuresbyid=patientregistret%2c%20socialstyrelsen&units=se>.
62. SOU 2017:4. För en god och jämlik hälsa - en utveckling av det folkhälsopolitiska ramverket, Delbetänkande från Kommissionen för jämlik hälsa.
63. Krieger N. Theories for social epidemiology in the 21st century: an ecosocial perspective. *Int J Epidemiol*. 2001;30(4):668-77.
64. Krieger N. Genders, sexes, and health: what are the connections--and why does it matter? *Int J Epidemiol*. 2003;32(4):652-7.
65. Hamberg K, Risberg G, Johansson EE. Male and female physicians show different patterns of gender bias: A paper-case study of management of irritable bowel syndrome. *Scandinavian journal of public health*. 2004;32(2):144-52.
66. Risberg G. "I am solely a professional – neutral and genderless": on gender bias and gender awareness in the medical profession: Umeå University medical dissertations; 2004.
67. Smirthwaite G. Genom genuslinser: Om patienters jämställdhet i tillgång till operation av gråstarr i Sverige: Gender Differences among Patients regarding Access to Cataract Extractions in Sweden: Linnéuniversitetet; 2016.

68. Smirthwaite G, Tengelin E, Borrmann T. (O)jämslälldhet i hälsa och vård: reviderad upplaga 2014: Sveriges Kommunder och Landsting SKL; 2014.
69. Ravn-Fischer A. Optimizing the early treatment of a threatening myocardial infarction. Gothenburg: Diss. Göteborg : Göteborgs universitet; 2013.
70. Ljungman C. Treatment of hypertension in women and men. Gothenburg: Diss. Göteborg : Göteborgs universitet; 2014; 2014.
71. Määttä S, Schenck-Gustafsson K, Trollvik M, Karlsson, Evengård B. Men costs more than women in myocardial infarction and appendicitis. *Lakartidningen*. 2015;112(18-19):898-901.
72. Raine R. Does Gender Bias Exist in the Use of Specialist Health Care? *Journal of health services research & policy*. 2000;5:237-49.
73. Nilsson H, Stylianidis G, Haapamäki M, Nilsson E, Nordin P. Mortality After Groin Hernia Surgery. *Annals of Surgery*. 2007;245(4):656-60.
74. Lind LK, Von Euler M, Korkmaz S, Gustafsson KS. Sex differences in drugs: the development of a comprehensive knowledge base to improve gender awareness prescribing. *Biology of sex differences*. 2017;8(1):32.
75. Schenck-Gustafsson K, Dahlin S. Underlag till Jämslälldhetsutredningen U2014:06 Hälsa. Stockholm; 2015.
76. Cylus J, Hartman M, Washington B, Andrews K, Catlin A. Pronounced gender and age differences are evident in personal health care spending per person. *Health affairs (Project Hope)*. 2011;30(1):153-60.
77. Wang Y, Hunt K, Nazareth I, Freemantle N, Petersen I. Do men consult less than women? An analysis of routinely collected UK general practice data. *BMJ open*. 2013;3(8):e003320.
78. Fan JX, Wen M, Jin L, Wang G. Disparities in Healthcare Utilization in China: Do Gender and Migration Status Matter? *J Fam Econ Iss*. 2013;34(1):52-63.
79. Johnson-Lans S, Bellemore F. Gender and race as factors in health care utilization. *Int Adv Econ Res*. 1997;3(2):193-205.
80. Pevalin DJ. Socio-economic inequalities in health and service utilization in the London Borough of Newham. *Public health*. 2007;121(8):596-602.
81. Bertakis KD, Azari R, Helms LJ, Callahan EJ, Robbins JA. Gender differences in the utilization of health care services. *The Journal of family practice*. 2000;49(2):147-52.
82. Kapur N, Hunt I, Lunt M, McBeth J, Creed F, Macfarlane G. Primary care consultation predictors in men and women: a cohort study. *The British journal of general practice : the journal of the Royal College of General Practitioners*. 2005;55(511):108-13.



83. Vaidya V, Partha G, Karmakar M. Gender differences in utilization of preventive care services in the United States. *Journal of women's health* (2002). 2012;21(2):140-5.
84. Grossman M. On the Concept of Health Capital and the Demand for Health. *Journal of Political Economy*. 1972;80(2):223-55.
85. Heintz E, Lintamo L, Hultcrantz M, Jacobson S, Levi R, Munthe C, et al. FRAMEWORK FOR SYSTEMATIC IDENTIFICATION OF ETHICAL ASPECTS OF HEALTHCARE TECHNOLOGIES: THE SBU APPROACH. *International Journal of Technology Assessment in Health Care*. 2015;31(3):124-30.
86. SOU 1995:5. Vårdens svåra val : slutbetänkande, Utredningen om prioriteringar inom hälso- och sjukvården. Stockholm: Fritze; 1995.
87. WHO. Mainstreaming gender equity in health: The need to move forward Geneva2002 [Available from: [http://www.euro.who.int/\\_data/assets/pdf\\_file/0008/76508/A75328.pdf](http://www.euro.who.int/_data/assets/pdf_file/0008/76508/A75328.pdf).
88. UN, United Nations. Important Concepts Underlying Gender Mainstreaming New York: ; 2001 [Available from: <http://www.un.org/womenwatch/osagi/pdf/factsheet2.pdf>.
89. Government Offices of Sweden, Gender equality policy goals 2017 [Available from: <https://www.government.se/government-policy/gender-equality/goals-and-visions/>.
90. Drummond MF, Sculpher MJ, Torrance GW, O'Brien BJ. *Methods for the economic evaluation of health care programmes*. 3 ed. Oxford: Oxford University Press; 2005.
91. Hicks J. The valuation of the social income. *Economica*. 1940;7:105-24.
92. Kaldor N. Welfare propositions of economics and interpersonal comparisons of utility. *Economic Journal*. 1939;49:549-52.
93. Johns Hopkins Medicine. What is renal failure? 2017 [Available from: [https://www.hopkinsmedicine.org/healthlibrary/conditions/kidney\\_and\\_urinary\\_system\\_disorders/end\\_stage\\_renal\\_disease\\_esrd\\_85,P01474](https://www.hopkinsmedicine.org/healthlibrary/conditions/kidney_and_urinary_system_disorders/end_stage_renal_disease_esrd_85,P01474).
94. National Institute of Diabetes and Digestive and Kidney Diseases. What Is Chronic Kidney Disease? 2017 [Available from: <https://www.niddk.nih.gov/health-information/kidney-disease/chronic-kidney-disease-ckd/what-is-chronic-kidney-disease>.
95. National Institute of Diabetes and Digestive and Kidney Diseases. Managing Chronic Kidney Disease 2016 [Available from: <https://www.niddk.nih.gov/health-information/kidney-disease/chronic-kidney-disease-ckd/managing>.
96. Klarenbach SW, Tonelli M, Chui B, Manns BJ. Economic evaluation of dialysis therapies. *Nature reviews Nephrology*. 2014;10(11):644-52.

97. Meguid El Nahas A, Bello AK. Chronic kidney disease: the global challenge. *Lancet* (London, England). 2005;365(9456):331-40.
98. The Swedish Psoriasis Association (Psoriasis förbundet) What is psoriasis? (Vad är psoriasis?) 2018 [Available from: <https://www.psoriasisforbundet.se/fakta-o-rad/om-psoriasis/>].
99. The Swedish Asthma and Allergy Association (Astma och Allergiförbundet), Atopic eczema (Atopiskt eksem) 2018 [Available from: <https://astmaoallergiforbundet.se/information-rad/atopiskt-eksem/>].
100. WHO. International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10), 1992. The Swedish translation, version 2011: National Board of Health and Welfare.
101. Griva K, Li ZH, Lai AY, Choong MC, Foo MW. Perspectives of patients, families, and health care professionals on decision-making about dialysis modality--the good, the bad, and the misunderstandings! *Peritoneal dialysis international : journal of the International Society for Peritoneal Dialysis*. 2013;33(3):280-9.
102. McLaughlin K, Manns B, Mortis G, Hons R, Taub K. Why patients with ESRD do not select self-care dialysis as a treatment option. *American journal of kidney diseases : the official journal of the National Kidney Foundation*. 2003;41(2):380-5.
103. Kazley AS, Hund JJ, Simpson KN, Chavin K, Baliga P. Health Literacy and Kidney Transplant Outcomes. *Progress in Transplantation*. 2015;25(1):85-90.
104. Kickbusch I. Health literacy: an essential skill for the twenty-first century. *Health Education*. 2008;108(2):101-4.
105. Kickbusch I. Health literacy: engaging in a political debate. *International journal of public health*. 2009;54(3):131-2.
106. Lai AY, Ishikawa H, Kiuchi T, Mooppil N, Griva K. Communicative and critical health literacy, and self-management behaviors in end-stage renal disease patients with diabetes on hemodialysis. *Patient Education and Counseling*. 2013;91(2):221-7.
107. Orwelius L, Nilsson M, Nilsson E, Wenemark M, Walfridsson U, Lundström M, et al. The Swedish RAND-36 Health Survey - reliability and responsiveness assessed in patient populations using Svensson's method for paired ordinal data. *Journal of Patient-Reported Outcomes*. 2017;2(1):1-10.
108. Navaie-Waliser HM, Spriggs HA, Feldman HP. Informal Caregiving: Differential Experiences by Gender. *Medical Care*. 2002;40(12):1249-59.
109. Roit B, Hoogenboom M, Weicht B. The gender informal care gap: a fuzzy-set analysis of cross-country variations. *European societies*. 2015;17(2):199-218.

110. Katz SJ, Kabeto M, Langa KM. Gender Disparities in the Receipt of Home Care for Elderly People With Disability in the United States. *Jama*. 2000;284(23):3022-7.
111. Langer A, Meleis A, Knaul FM, Atun R, Aran M, Arreola-Ornelas H, et al. Women and Health: the key for sustainable development. *The Lancet*. 2015;386(9999):1165-210.
112. Ostlin P, Sen G, George A. Paying attention to gender and poverty in health research: content and process issues. *Bulletin Of The World Health Organization*. 2004;82(10):740-5.
113. Ruiz MT, Verbrugge LM. A two way view of gender bias in medicine. *Journal of epidemiology and community health*. 1997;51(2):106.
114. Verdonk P, Benschop Y, Haes H, Lagro-Janssen T. From gender bias to gender awareness in medical education. *Advances in Health Sciences Education*. 2009;14(1):135-52.
115. SKL, Sveriges Kommuner och Landsting, National mission: pain (Nationellt uppdrag: Smärta) Stockholm2016 [Available from: <https://webbutik.skl.se/bilder/artiklar/pdf/7585-444-1.pdf?issuusi=ignore>.
116. Kowalski C, Lee S-YD, Schmidt A, Wesselmann S, Wirtz MA, Pfaff H, et al. The health literate health care organization 10 item questionnaire (HLHO-10): development and validation. *BMC health services research*. 2015;15(1):47.
117. Stock S, Altin S. Health Literate Healthcare Organizations and their Role in Future Healthcare. *Journal of Nursing & Care*. 2015;04(02).
118. Sorensen K, Broucke vdS, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. (HLS-EU) Consortium Health Literacy Project European health literacy and public health: a systematic review and integration of definitions and models. *BMC public health*. 2012;25(12):80.

# Appendix

The questionnaire was discussed in two research groups at the Section for Epidemiology and Social Medicine at the Sahlgrenska academy and assessed by researchers in nephrology and health literacy. The questionnaire was then tested in a pilot study with 10 dialysis patients living outside the Region (VGR) recruited via an inquiry to the Swedish Kidney Association's Facebook group and improvement was made in accordance with views expressed through written comments and telephone discussions with the patients.

## Alla frågor i enkäten

Frågornas ursprung är angiven på höger sida eller i början av de olika enkätavsnitten. Svartalternativen har utelämnats av utrymmesskäl.

### *Bakgrund*

1. Vilket år är du född (SCB, Frågebank över bakgrunds-
2. Är du man eller kvinna (frågor, SCB 2004:2 m.fl.)
3. Vilken typ av bostad bor du i (SCB 2004 m.fl.)
4. Med vem delar du bostad (SCB 2004 m.fl.)
5. Finns det barn i hushållet (SCB 2004 m.fl.)
6. Vilken är din högsta genomförda utbildning (SCB 2004 m.fl.)
7. Inom vilket yrkesområde har du huvudsakligen arbetat  
(Arbetsförmedlingen, lista över yrkesområden,  
se <http://www.arbetsformedlingen.se/>)
8. Vilket är eller har varit ditt huvudsakliga yrke? (SCB 2004 m.fl.)
9. Har du genomgått dialysbehandling de senaste 7 dagarna
10. Vilket modersmål har du (Client service receipt  
inventory (CSRI) se  
nedan.)
11. Om du har annat modersmål än svenska: Ange med vilka kontakter eller i  
vilka sociala sammanhang du talar svenska. (Hälsolitteracitet)
12. Förvärvsarbetar du för närvarande (Arbetsbelastning, Ulf Lundberg)
13. Om du inte skulle behöva genomgå dialysbehandling skulle du då ägna  
mer tid till förvärvsarbete.

### ***Sjukdom***

(Huvudsaklig källa är samtal med och återkoppling på utkast till enkätfrågor från en grupp av forskare och kliniker inom området njurmedicin och dialysbehandling.)

- 14. Vilken är din njursjukdom (ULF/SILC 2014 SCB)
- 15. Vilket år blev du diagnostiserad med njursjukdom
- 16. Har du någon annan långvarig eller allvarlig sjukdom förutom din njursjukdom
- 17. Har du genomgått någon operation i magen/buken innan det blev aktuellt med dialys för dig

### ***Dialysbehandling***

(Huvudsaklig källa är samtal med och återkoppling på utkast till enkätfrågor från en grupp av forskare och kliniker inom området njurmedicin och dialysbehandling.)

- 18. När började du med dialysbehandling
- 19. När hade du senast en dialysrelaterad infektion eller annan komplikation
- 20. Vilken dialysbehandling har du för närvarande
- 21. Sedan när har du haft den dialysbehandling du har för närvarande
- 22. Hur ofta dialyserar du en genomsnittlig vecka
- 23. Hur lång tid tar i genomsnitt din dialysbehandling per gång
- 24. Har du haft någon annan form av dialysbehandling än den du har för närvarande

### ***Hälso- och sjukvårdskontakter***

(Client Service Receipt Inventory, CSRI är ett standardformulär för att mäta resursanvändning (Beecham & Knapp, 1992 & 2001; Chisholm et al., 2000). Flera CSRI enkäter som använts i publicerade studier användes i utformningen av nedanstående frågor).

- 25. Under de senaste 3 månaderna vilka personliga besök har du gjort på vårdcentralen på grund av din njursjukdom eller dialys eller med anledning av komplikationer av dessa
- 26. Under de senaste 3 månaderna vilka personliga dagbesök har du gjort på specialistmottagning/sjukhus på grund av din njursjukdom eller dialys eller med anledning av komplikationer av dessa
- 27 a. Har du under de senaste 3 månaderna varit inlagd på sjukhus på grund av din njursjukdom eller dialys eller med anledning av komplikationer av dessa
- 27 b. Om ja, fyll i detaljerna för varje tillfälle

***Ej receptbelagda läkemedel, naturläkemedel, vitaminer, kosttillskott etc.***  
(CSRI se ovan)

28. Skriv ner de ej receptbelagda läkemedel, naturläkemedel, vitaminer och kosttillskott som du använder p.g.a. din njursjukdom och/eller dialys
29. Har du haft några andra personliga utgifter med anledning av din njursjukdom eller dialys de senaste 3 månaderna, utöver patientavgifter i hälso- och sjukvården och läkemedel/kosttillskott?

***Transport***

(CSRI, se ovan)

30. Hur transporterar du dig vanligen till njurmottagningen/  
dialysmottagningen/PD-mottagningen
31. Ungefär hur lång är resan enkel väg?

***Hjälp och stöd i hemmet***

(RIKS-STROK och CSRI, se ovan)

32. Får du hjälp av hemtjänst, hemsjukvård eller annan hjälp med anledning av din njursjukdom

***Hjälp och stöd av närstående***

(RIKS-STROK och CSRI se ovan)

33. Får du stöd eller hjälp av anhörig/närstående i din vardag med anledning av din njursjukdom/dialys
34. Hur lång tid får du aktivt stöd av en anhörig/närstående en genomsnittlig vecka

***Information, erfarenheter och åsikter***

(Frågorna är framtagna i samarbete med forskare inom hälsolitteracitet och på basis av studier om hälsolitteracitet samt studier kring barriärer mot olika dialysmetoder; Griva et al., 2011 and McLaughlin et al., 2003 och genom samtal med och återkoppling på utkast till enkätfrågor från en grupp av forskare och kliniker inom området njurmedicin och dialysbehandling.)

35. På vilket sätt fick du information om dialysbehandling innan du påbörjade din dialys
36. Här kommer att antal påståenden om den information du fått som vi vill att du tar ställning till
1. Jag fick information om olika dialysmetoder
  2. Det gavs tillräcklig information om HD på sjukhus/mottagning
  3. Det gavs tillräcklig information om hem HD
  4. Det gavs tillräcklig information om manuell PD
  5. Det gavs tillräcklig information om automatisk PD (nattmaskin)

6. Det gavs tillräcklig information om assisterad PD
7. Jag hade behövt information om dialys vid fler tillfällen
8. Jag hade behövt mer grundlig information
9. Den information jag fick var lätt att förstå
10. Utifrån den information jag fick var jag redo att fatta beslut om dialysmetod
11. Det är relevant att jag själv fattar beslut om dialysmetod
12. Jag skulle uppskattat information på annat sätt än på det sätt jag fick, exempelvis via datorn, via app i telefonen, via DVD film eller broschyr
37. Jag har den dialysform jag har idag för att:
38. Vilka påståenden anser du påverkar valet av dialysmetod
  1. Vid HD på mottagning får man hjälp och stöd av sjukvårdspersonal flera gånger i veckan
  2. HD behandling på mottagning är tidskrävande
  3. Tätare dialyser vid hem HD och PD innebär att man mår bättre
  4. Hem HD och PD innebär att det blir en sjukvårdsmiljö i hemmet
  5. Vid PD är det besvärande med en kateter i magen
  6. PD har medicinska fördelar jämfört med andra dialysalternativ
  7. Hem HD och PD kräver större eget ansvar
  8. Vid PD är det besvärande att ha dialysvätska i magen
  9. Hem HD har medicinska fördelar jämfört med andra dialysalternativ
  10. Hem HD och PD är krångligt och svårt att sköta
  11. Manuell PD är besvärande i sociala sammanhang
  12. HD på mottagning har medicinska fördelar jämfört med andra dialysalternativ
  13. PD innebär att man behöver ägna mindre tid till dialys jämfört med andra dialysalternativ
  14. PD hämmar/stör samlivet
  15. Hem HD och PD belastar familj och närstående
  16. Hem HD och PD kräver mycket utrymme i hemmet
  17. Med HD på mottagning är man helt fri från behandling en del dagar i veckan
  18. Hem HD och PD innebär högre egna utgifter
  19. HD på mottagning innebär att man regelbundet träffar personal och andra patienter.
39. Vilken dialysbehandling anser du ger patienten störst frihet
40. Vilken dialysbehandling anser du ger patienten störst trygghet
41. Finns det fler åsikter eller faktorer som kan påverka val av dialysbehandling:

### **RAND-36 Hälsa och livskvalitet**

RAND-36 är ett generiskt instrument för att mäta hälsorelaterad livskvalitet och kan beställas av Register Centrum SydOst. Instrumentet innehåller 36 frågor där samtliga frågor har flera svarsalternativ (från 2–6).

1. I allmänhet, skull du säga att din hälsa är
2. Jämfört med för ett år sedan, hur skulle du bedöma din hälsa nu

Begränsar din nuvarande hälsa dig i dessa aktiviteter:

3. Fysiskt ansträngande aktiviteter
4. Måttligt ansträngande aktiviteter
5. Lyfta eller bära matkassar
6. Gå upp för flera trappor
7. Gå upp för en trappa
8. Böja dig eller gå ner på knä
9. Gå mer än ett par kilometer
10. Gå fler kvarter
11. Gå ett kvarter
12. Bada/duscha eller klä på dig

Under de senaste 4 veckorna, har du haft något av följande problem med ditt arbete eller andra vanliga dagliga aktiviteter på grund av din fysiska hälsa:

13. Dragit ner på tiden du ägnat åt arbete eller andra aktiviteter
14. Fått mindre gjort än du skulle vilja
15. Begränsats i vissa arbetsuppgifter eller andra aktiviteter
16. Haft svårt att utföra arbete eller andra aktiviteter

Under de senaste 4 veckorna har du haft något av följande problem med ditt arbete eller andra vanliga dagliga aktiviteter på grund av känslomässiga problem

17. Dragit ner på tiden du ägnat åt arbete eller andra aktiviteter
18. Fått mindre gjort än du skulle vilja
19. Utfört arbete eller andra aktiviteter mindre noggrant än vanligt
20. Under de senaste 4 veckorna, i vilken omfattning har din fysiska hälsa eller känslomässiga problem stört din vanliga sociala aktivitet med familj, släkt, vänner, grannar eller föreningar etc.
21. Hur mycket fysisk smärta har du haft under de senaste 4 veckorna
22. Under de senaste 4 veckorna, hur mycket har smärta stört ditt vanliga arbete (gäller både arbete utanför hemmet och hushållsarbete)

Följande frågor handlar om hur du känner dig och hur det har varit under de senaste 4 veckorna



- 23. Har du känt dig pigg
- 24. Har du känt dig mycket nervös
- 25. Har du känt dig så nere att ingenting kunnat muntra upp dig
- 26. Har du känt dig lugn och harmonisk
- 27. Har du känt dig energisk
- 28. Har du känt dig dystert och ledsen
- 29. har du känt dig lycklig
- 31. Har du känt dig trött
- 32. Under de senaste 4 veckorna, hur mycket av tiden har din fysiska hälsa eller känslomässiga problem stört dina sociala aktiviteter

Hur väl stämmer följande påståenden in på dig

- 33. Jag verkar ha något lättare att bli sjuk än andra människor
- 34. Jag är lika frisk som andra som jag känner
- 35. Jag tror min hälsa kommer att försämrats
- 36. Min hälsa är utmärkt

42. Får vi lov att vid ett senare tillfälle kontakta dig om vi har fler frågor om dina erfarenheter av dialysbehandling?

Är det någonting Du skulle vilja berätta som inte nämnts i enkäten eller något Du vill komplettera som tagits upp i enkäten, skriv gärna några rader om det i fältet nedan

